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# **The Emergence of the Carer: Mental Health Care in England and Wales, c. 1946-1999**

**by**

**Claire Sewell**

**A thesis submitted in fulfilment of the requirements for the degree of  
Doctor of Philosophy in History**

**University of Warwick,  
Department of History,  
Centre for the History of Medicine  
March 2015**

# Table of Contents

<b>Acknowledgements.....</b>	<b>iii</b>
<b>Declaration .....</b>	<b>iv</b>
<b>Abstract.....</b>	<b>v</b>
<b>Abbreviations .....</b>	<b>vi</b>
<b>Introduction.....</b>	<b>1</b>
Definitions and Methodology .....	7
i. Definitions .....	7
ii. Themes and Methodology .....	8
Historiography of Family Carers.....	13
i. Nineteenth Century Psychiatry and the Family .....	13
ii. Destabilising the History of Community Care .....	18
iii. Towards a History of the Family Carer .....	31
Post-War British Historiography .....	38
i. The Welfare State .....	38
ii. Voluntary Action .....	41
iii. The Post-War Family .....	45
iv. Sociology, Psychology, and the Psychosocial .....	51
Source-Base and Thesis Outline.....	57
i. Source-Base.....	57
ii. Thesis Outline .....	60
<b>1.....</b>	<b>64</b>
<b>The Family Carer as an Object of Social Policy, c. 1954-1999 .....</b>	<b>64</b>
The <i>Better Services</i> white papers, c.1954-1975.....	69
The Invalid Care Allowance, c.1971-1986.....	80
Contesting Community Care, c. 1983-1990 .....	94
Carers Enacted, c.1995-1999 .....	108
Conclusions .....	115
<b>2.....</b>	<b>118</b>
<b>The Identification of the Family Carer as a Subject of Social Research, c. 1956-1998.....</b>	<b>118</b>
Home-based Family Interviews, c. 1956-1970.....	123
Expressed Emotion, c. 1958-1985.....	136

The General Household Survey: 1985, 1990, and 1995.....	155
Conclusions .....	164
<b>3.....</b>	<b>167</b>
<b>Television and Film Representations of the Family Carer, c. 1960-1999.....</b>	<b>167</b>
Parent Groups and Documentary Film, c. 1960-69.....	172
Documentary-drama and Anti-Psychiatry, c. 1964-1972.....	183
Channel 4 and Carer Voice, c. 1982-1999 .....	196
Conclusions .....	203
<b>4.....</b>	<b>206</b>
<b>Mencap and the Family Carer, c. 1946-1999 .....</b>	<b>206</b>
Early Years: NAPBC, c. 1946-1955.....	208
Parents as Experts: NSMHC, c. 1959-1979.....	223
Respite for Carers: Mencap, c. 1981-1996.....	237
Conclusions .....	245
<b>5.....</b>	<b>248</b>
<b>The National Schizophrenia Fellowship and the Family Carer, c. 1971-1999 .....</b>	<b>248</b>
The Early Years of the NSF, c. 1971-74 .....	250
The NSF and MIND, c. 1971-1987 .....	261
Equal Partners, c. 1987-1999 .....	276
Conclusions .....	289
<b>6.....</b>	<b>292</b>
<b>Post-war History of Mental Illness and Learning Disability: The Family Carer as Case Study .....</b>	<b>292</b>
Mental Illness and Mental Handicap: Towards a New Historiography .....	294
The Place of Mental Handicap in Post-War Mental Health Care.....	297
A New Perspective on the History of the Family Carer.....	305
Conclusions .....	315
<b>Conclusion .....</b>	<b>317</b>
Thesis Summary and Discussion .....	317
i. Making Up the Carer? .....	318
ii. Key Themes .....	321
Epilogue: Unpaid Carers, c. 2000-2011.....	327
<b>Bibliography .....</b>	<b>335</b>

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## **Declaration**

I hereby declare that this thesis has not been submitted, either in the same or different form, to this or any other University for a degree.

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# Abstract

This thesis examines the emergence of the family carer in English and Welsh mental health care, from the inception of the National Association for the Parents of Backwards Children in 1946 until the publication of the National Strategy for Carers in 1999. Rather than being primarily concerned with the day-to-day experiences of these family care-givers, the focus of this thesis, drawing upon Professor Ian Hacking's theories as a starting point, is on the history of ideas and the emergence of the family carer as a category. With specific reference to familial care of relatives with a mental illness or a learning disability, I consider how and why the term 'carer' did not come into widespread usage until the 1980s. As the British government moved towards an explicit policy of deinstitutionalisation and community care in the 1960s, concern was raised that care *in* the community would in reality mean care *by* the family. For some this was a concern because they were worried about the well-being of the affected families, whilst for others they were concerned about the potential pathological impact of the family. Through this qualitative study of the family carer, I argue that whilst families have cared for relatives with mental illnesses and learning disabilities for centuries, during the post-war years this role was discussed, acknowledged, politicised, negotiated, and challenged to a much greater extent. Indeed, by 1999 family carers were recognised in their own right rather than exclusively in relation to the person they cared for. The story of the emergence of the family carer contributes to, and in some respects destabilises, current literature on the histories of mental health care, community care, the family, the psychosocial, the welfare state, and voluntary action.

# Abbreviations

AGM	Annual General Meeting
BBC	British Broadcasting Corporation
DH	Department of Health
DHSS	Department of Health and Social Security
DKP	Derrick Knight & Partners
DSA	Down's Syndrome Association
GHS	General Household Survey
HAS	Health Advisory Service
HMSO	Her Majesty's Stationary Office
ICA	Invalid Care Allowance
IQ	Intelligence Quotient
LSE	London School of Economics and Political Science
LSEA	LSE Archives and Special Collections, London
MH	Ministry of Health
MP	Member of Parliament
MRC	Modern Records Centre, University of Warwick
NAPBC	National Association for the Parents of Backwards Children
NAMH	National Association of Mental Health
NCSWD	National Council for Single Women and her Dependents
NGO	Non-Governmental Organisation
NHS	National Health Service
NSATC	National Society for the Aid of Thalidomide Children
NSF	National Schizophrenia Fellowship
NSS	National Spastics Society
ONS	Office of National Statistics
SMO	Social Movement Organisation
SPRU	Social Policy Research Unit
SPU	Medical Research Council's Social Psychiatry Unit
TNA	The National Archives, London
WL	The Wellcome Library Archives and Manuscripts, London

# Introduction

The term 'carer' to refer to relatives providing care for a family member came into widespread use during the early 1980s. In 1985 the Office of National Statistics' General Household Survey included a section of questions on informal care for the first time. The survey defined informal carers as 'people who are looking after, or providing some regular service for, a sick, handicapped or elderly person living in their own or another household'.<sup>1</sup> The report which followed the 1985 survey indicated that that one in seven adults were providing informal care in one in five households, which amounted to an estimated total of six million carers throughout Britain once the survey results had been extrapolated to the population at large.<sup>2</sup> Of course, family care-giving was not a new phenomenon. Evidence exists that relatives have provided care for sick, handicapped, and elderly relatives within the family unit for many centuries.<sup>3</sup> Historian Peregrine Horden has stated that: 'British Historiography offers probably the longest and more or less continuous narrative of informal relief arrangements - from the thirteenth century onwards.'<sup>4</sup> What was new in the post-war period, however, was the development of concise definitions

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<sup>1</sup> Hazel Green, *Informal Carers: A Study carried out on behalf of the Department of Health and Social Security as part of the 1985 General Household Survey* (London, 1988), p. 1.

<sup>2</sup> Green, *Informal Carers* (1988), p. 1.

<sup>3</sup> For a long-view of the history of informal care see: Peregrine Horden and Richard Smith (eds), *The Locus of Care: Families, Communities, Institutions, and the Provision of Welfare since Antiquity* (London, 1998). In particular, see the volume's introduction: Peregrine Horden, 'Household Care and Informal Networks: Comparisons and Continuities from Antiquity to the Present', in Horden and Smith, *The Locus of Care*, pp. 21-67.

<sup>4</sup> Horden, 'Household Care', p. 44.

and expectations for the role of care-givers within mental health care, often configured around the number of hours spent caring in a week. During the post-war years, care provided by relatives was counted, politicised, surveyed, publicised, and supported in new ways and on a national scale.

In this thesis, I focus on the history of the emergence and development of the category of the family carer during the post-war period in England and Wales, with specific reference to the care of the mentally ill and mentally handicapped. This thesis is not therefore centrally concerned with the everyday experiences of family carers, though it does cast light on this subject. My focus is on families, and in particular parents, caring for children and adolescents. As historian Mathew Thomson has argued, the place of the family in mental health care has been largely overlooked by historians of post-war Britain. Psychosocial studies academic David W. Jones has made the same claim for the role of families in the discipline of psychiatry itself.<sup>5</sup> The history of the carer provides a way to interrogate not only the interplay between the family and mental health care or psychiatry, but also a range of other phenomena important to our understanding of the post-war state, including social welfare and voluntary action.

This thesis covers the period between 1946 and 1999. There are two reasons for starting the analysis in 1946. Firstly, the aftermath of the Second World War was a moment of significant social and political change in Britain, especially the emergence of the new welfare state, and this start date enables the thesis to cast further light on the implications of these changes through a case study of mental

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<sup>5</sup> David W. Jones, 'Madness, the Family and Psychiatry', *Critical Social Policy*, 22 (2002), p. 247; Mathew Thomson, *The Problem of Mental Deficiency: Eugenics, Democracy and Social Policy in Britain c. 1870-1959* (Oxford, 1998), p. 2.

health care. Secondly, 1946 was the year that the National Association for the Parents of Backwards Children (NAPBC, later Mencap) was incepted. The NAPBC was the first national parent organisation for mental illness or mental handicap to emerge in Britain and as such marks an important moment in the history of the family carer, particularly in relation to voluntary action. The end date of 1999 has been selected because it saw the publication of the National Strategy for Carers, *Caring about Carers*. This strategy marked an important shift in the state's view of the family carer, by not only acknowledging the key role they played in community care, but also that carers had needs in their own right. By spanning just over five decades, this thesis is able to examine broad shifts which occurred in relation to the place of the carer in mental health care.

The geographical scope of this thesis has been delimited to England and Wales. This is in part because of legislative differences between the different nations in the United Kingdom, especially towards the latter decades of the twentieth century. Another reason for this is that the carer organisations I am going to examine, Mencap and the NSF, had Scottish and Northern Irish equivalents. The story told here is largely a national one, but where appropriate regional and local examples will be utilised.

There are two central questions in this thesis. Firstly, what was the meaning, significance, and implications of the emergence of the family carer in the field of mental health care in the post-war years? Secondly, how was this emergence of the family carer similar and different from what had come before. By answering these central questions, I demonstrate that the study of the history of the family carer can contribute to a number of historical fields. The thesis speaks to the histories of

the family, psychiatry, mental health care, the psychosocial, non-governmental organisations, the welfare state, voluntary action, and community care in post-war Britain. This is possible because the history of the carer in post-war England and Wales, I argue, intersects with a number of phenomena newly introduced, reconceptualised, or in flux in the second half of the twentieth century. These phenomena, which at first glance appear somewhat disparate, include:

demographic change, social movement mobilisation, new academic disciplines and methodologies, the media of film and television, and the welfare state. Similarly to the approach suggested by scholars of, what they have chosen to term, Modern British Studies at the University of Birmingham, this thesis could be said to be interested in the various 'cultures of democracy' that contributed to the emerging category of the family carer. The term cultures of democracy refers to the new opportunities, mechanisms, and social and cultural conditions for facilitating democratic participation in the period.<sup>6</sup> This thesis highlights and examines the roles of voluntary action, social policy, the media, and social scientific research in the emergence of this culture of democracy, and it assesses the degree to which this culture was crucial in the emergence of the family carer. On the other hand, the thesis also looks beyond the cultures of democracy as catalysts for development. In particular, it assesses the extent to which it was not cultures of democracy, but new ways of seeing, studying, counting, feeling, and being, which make the post-war years in England and Wales distinctive.<sup>7</sup> Here, as recognised by Foucauldians

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<sup>6</sup> Centre for Modern British Studies, 'Modern British Studies at Birmingham Working Paper No. 1', February 2014. <<http://www.birmingham.ac.uk/Documents/college-artslaw/history/mbs/MBS-Birmingham-Working-Paper-1.pdf>> (9 November 2014).

<sup>7</sup> Rhodri Hayward, *The Transformation of the Psyche in British Primary Care 1880-1970* (London, 2014); Nikolas Rose, 'Psychology as a Social Science', *Subjectivity*, 25:1 (2008), p. 452-53; Mike

from David Armstrong to Ian Hacking, the power of the survey combined with certain state mechanisms to create and imbue the category of the carer with social meaning and a material basis.

It needs to be acknowledged at the start that the history of the family carer in the post-war period connects with a much longer-term history of mental health care within the domestic sphere. Historian Philippa Levine has argued that although there is a growth in scholarship on the post-war years this period does not constitute a natural break.<sup>8</sup> I accept this, even if the focus on the post-war era inevitably brings post-war change into focus. In the Introduction, I will step back to consider the question of longer development and continuities. In the chapters which follow, the thesis does not therefore treat the post-war period as a definitive, absolute, break or turning point in the history of family care-giving. However, I will argue that there were significant changes in the place of the carer in mental health care in the post-war years, even though these changes had antecedents in the nineteenth and earlier-twentieth century. I also suggest that, regardless of whether the reality of life in post-war England and Wales had certain continuities with what had come before, the actors who appear in this thesis found new ways to express, discuss, and experience familial care-giving after the Second World War.

Whilst caring has taken place within the family for many centuries, it was not until the 1960s and 1970s that this caring role came to be acknowledged explicitly and commented upon by the media, social policy makers, and medical

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Savage, *Identities and Social Change in Britain since 1940: The Politics of Method* (Oxford, 2010); Mathew Thomson, *Psychological Subjects: Identity, Culture, and Health in Twentieth Century Britain* (Oxford, 2006).

<sup>8</sup> Philippa Levine, 'Decline and Vitality: The Contradictions and Complexities of Twentieth-Century Britain', *Twentieth Century British History*, 21:3 (2010), pp. 396-404.

professionals.<sup>9</sup> The most significant shifts in this regard came in terms of state policy during the early and mid-1970s with the publication of two government white papers explicitly referring to the care provided by families of the mentally handicapped and the mentally ill. These documents, *Better Services for the Mentally Handicapped* (1971) and *Better Services for the Mentally Ill* (1975), shortly followed by the introduction of the Invalid Care Allowance (1976), signify the beginning of a much broader shift towards the emergence of the category of the carer.

A key example of the popularity of the term carer by the 1980s, for instance, was the 1985 General Household Survey's special study into the phenomenon of 'informal care' provided by families, seeking for the first time, 'to provide national estimates of the number of informal carers and to describe their characteristics'.<sup>10</sup> This followed indications that community care policies and an ageing population would increase the numbers of informal carers.<sup>11</sup> By the late 1980s carers were posited as the main providers of community care. The white paper *Caring for People: Community Care in the Next Decade and Beyond* (1989) 'acknowledge[d] that the bulk of care of people with disabilities, including those with considerable disabilities, falls on family, friends and neighbours. The role of the informal carer is vital.'<sup>12</sup>

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<sup>9</sup> Horden, 'Household Care', p. 44.

<sup>10</sup> Hazel Green, *Informal Carers: A Study carried out on behalf of the Department of Health and Social Security as part of the 1985 General Household Survey* (London, 1988), p. 4.

<sup>11</sup> *Ibid.*, p. 4.

<sup>12</sup> Department of Health and Department of Social Security, *Caring for People: Community Care in the Next Decade and Beyond* (London, 1988), Cm. 849.



## **Definitions and Methodology**

### **i. Definitions**

Wherever possible the terminology used within this thesis will be that used by contemporaries. Therefore, when discussing mental illness, the terms 'mental disorder', 'mental health', 'mental illness', or specific diagnoses will be used. During discussions of learning disability, the terms 'mental deficiency', 'mental handicap', 'learning disability', or specific conditions will be used. When I am making a broad point which covers all of the period studied, I will use the terms mental illness or learning disability, respectively. Whilst other scholars have used the term 'mental disorder' when speaking about mental illness and learning disability collectively, I have opted to avoid the use of this phrase because it lacks meaning and specificity. Indeed mental disorder is variably used to refer to mental illness and learning disability in conjunction, or just to mean mental illness. The term 'carer' to refer to care provided for relatives with a mental illness, mental handicap, or disability, did not enter widespread usage until the mid-1980s. Since then, the term 'informal carer' was generally used until the 1990s when the terms 'private carer' and 'family carer' became more popular. Again, I will use the most appropriate term. For the period before the mid-1980s, I will use the term 'relative', 'parent', 'mother', 'father', 'family care-giver', and 'familial care'.

## **ii. Themes and Methodology**

This thesis adopts a thematic structure with chapters on social policy, social scientific research, film and television, parent and carer organisations, and the distinction between mental illness and learning disability. This structure allows me to assess the influence of these factors in shifting the role and conceptualisation of the carer in post-war era. I will conclude that social policy was a key context in which the family carer for people with mental illnesses and learning disabilities emerged in post-war England and Wales. Moves towards the closure of institutions and a policy of community care, along with legislation and benefits aimed at family care-givers led to the official recognition of this group. However, I also stress that the other factors examined in this thesis played a central role in shaping, negotiating, and challenging the decisions made by social-policy makers.

Although the primary theme of the thesis is the history of the carer, the analysis also casts significant light on two subsidiary themes: the history of community care and the division between mental illness and mental handicap. In addressing these themes, the thesis also contributes a fresh perspective to our understanding of the nature, place, and expectations of the family in post-war Britain. Finally, the thesis has implications for how we may need to think differently about how we approach the history of mental health care as it moves into the post-war era. In particular, the analysis that follows indicates that the study of mental health care in isolation is problematic, because in the post-war era mental health care came to be deeply influenced by a number of factors external to mental health care itself, including social policy decisions on related but different sections of the

population, media representations, and social scientific research. In addition, a limited focus on the history of the mentally ill, which has characterised work on the history of mental health, has tended to conceal the histories of both the carer and of learning disability. This thesis also looks to the way that insight drawn from the history of the emotions can be brought together with a history of mental health policy.

Historians and sociologists working in the field of the history of the emotions offer a toolkit which can be utilised by historians to better understand the preoccupation of post-war researchers with social relationships, including relationships within the family.<sup>13</sup> An especially useful theory for this thesis is Barbara E. Rosenwein's concept of the "'emotional community'".<sup>14</sup> This concept enables me to explore relationships and emotions within social communities, including families and parent and carer organisations, during the post-war years when the emotions were understood as a psychological category.<sup>15</sup> It will also help me to cast light on contemporary interest and concern about parent and carer support groups, the pathology of the family, and the well-being of carers, all of which have a key role in the history of mental health care in the post-war period.

A central methodological challenge for this thesis is attending to the significance of the emergence of the category and language of the 'carer', while recognising that in some respects this role preceded the common or official use of

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<sup>13</sup> Thomas Dixon, *From Passions to Emotions: The Creation of a Secular Psychological Category* (Cambridge, 2006); Jan Plamper, 'The History of Emotions: An Interview with William Reddy, Barbara Rosenwein, and Peter Stearns', *History and Theory*, 49 (May 2010), pp. 237-65; Barbara H. Rosenwein, 'Worrying about Emotions in History', *American Historical Review*, 107:3 (2005), pp. 821-45.

<sup>14</sup> Rosenwein, 'Worrying', p. 284.

<sup>15</sup> Dixon, *Passions*, p. 1.

the term. Changes in the use of language around care-giving are important to the history of the emergence of the family carer, but also of importance were the changes to the everyday experience of carers, and there is a danger of neglecting this in a history that centres on official categorisation. Whilst the everyday experiences of those who came to be known as carers were affected by an emergent new language around caring, these changes were not confined to language alone. For instance, the term 'carer' did not enter widespread usage until the mid-1980s, but parent and carer organisations began to emerge from the mid-1940s onwards. To take a social constructionist approach which would suggest that 'carer' was a largely hollow and constructed category would be to overlook the everyday experiences of care-givers, a phenomenon with a longer history than the relatively recent term 'informal carer' would suggest. Further, I want to be able to examine how social changes affected those that became known as carers in the post-war period.

In order to overcome these issues this thesis takes as its point of departure the theory philosopher Ian Hacking developed as part of his 'Making Up People' project.<sup>16</sup> A central aspect of this theory is Hacking's definition of 'dynamic nominalism' as a form of co-production in which 'a kind of person [is said to come] into being at the same time as the kind itself was being invented'. As Hacking suggests, 'in some cases, that is, our classifications and our classes conspire to

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<sup>16</sup> For proceedings of a recent conference on the current relevance of the Making Up People project to scholars from various disciplines, including history, see: Jennifer Crane and Claire Sewell, "'Made Up People': An Interdisciplinary Approach to Labelling and the Construction of People in Post-War History', *Exchanges: The Warwick Research Journal*, 1:2 (2014).

emerge hand in hand, each egging the other on'.<sup>17</sup> Hacking has argued that once new categories of people became acknowledged they then became 'moving targets' as they changed in reaction to political, medical, and social classifications.<sup>18</sup> The process is cyclical, because these changes also change the nature of the category itself. As Hacking states, 'names interact with the named'. He refers to this as the 'looping effect'.<sup>19</sup> In the conclusion to this thesis I will return to Hacking's work to discuss how far the case of the family carer applies to the theories associated with the making up people project. Whilst there is a history of the carer before the term itself emerged, which does not fit neatly with Hacking's framework, his theory provides a useful starting point. Moreover, the emergence of the term 'carer' into widespread usage in the early 1980s can be seen as marking a new era in the history of the family carer, with the carer afforded greater social and political recognition. I argue that Hacking's theories remain useful to historians, especially as they provide a route into the social and political history of different types of people at a time when neuroscientific understandings of what it is to be human are becoming increasingly popular.

To examine the history of the family carer in the context of post-war mental health care in England and Wales, and to develop a case study to test Hacking's model, I consider the factors which led to the creation, emergence, awareness and

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<sup>17</sup> Ian Hacking, 'Making Up People' in Thomas C. Heller, Morton Sosna, and David E. Wellbery (eds), *Reconstructing Individualism: Autonomy, Individuality, and the Self in Western Thought* (Stanford, 1986), p. 228.

<sup>18</sup> Ian Hacking, 'Making Up People', *London Review of Books*, 28:16 (2006), pp. 23-26; Ian Hacking, 'Kinds of People: Moving Targets', *Proceedings of the British Academy*, 151 (2007), pp. 285-318.

<sup>19</sup> Hacking, 'Making Up' (2006), pp. 23-26; Ian Hacking, *The Social Construction of What?* (Cambridge, 1999), pp. 160-61.

negotiation of caring as a category, or label.<sup>20</sup> These include contemporary debates and concerns surrounding 'community care', sociological surveys investigating the role of the family in care-giving, media representations of familial carers, and the role of parent and carer organisations. I argue that the label and the category of the carer emerged at a time when the familial caring role was in flux, in terms of both expectations and day-to-day experience. Following the emergence of the category of the carer, those who were perceived as or considered themselves to be part of this group, along with other interested parties, negotiated and challenged this label, changing understandings of the carer once again.

The carer I therefore argue is not a natural category or 'kind'. 'To say that a kind is *natural* is to say that it corresponds to a grouping or ordering that does not depend on humans.'<sup>21</sup> However, familial caring is often treated as a natural, human instinct, usually attributed to women, rather than a role created by society. Despite this rhetoric, family care-giving and the family carer are both very much dependent on society which shapes the norms, expectations, social security benefits, child development stages, etc. In 2007, Hacking argued that neither natural kinds, or his previously preferred term 'human kinds', i.e. depending on humans, were useful, because they were ill-defined.<sup>22</sup> Instead, Hacking began to employ the term 'kinds of people' which helps to overcome the issue of designating a kind as either natural or human.

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<sup>20</sup> Ian Hacking, 'Making Up People' in Mario Biagioli (ed.), *The Science Studies Reader* (London and New York, 1999), p. 165. For further consideration of these ideas see Hacking, *The Social Construction of What?*. For more on co-production, see Sheila Jasanoff (ed.), *States of Knowledge: the Co-Production of Science and the Social Order* (2nd edn, London, 2006).

<sup>21</sup> Alexander Bird and Emma Tobin, 'Natural Kinds', *The Stanford Encyclopaedia of Philosophy* (Winter 2012 Edition). <<http://plato.stanford.edu/archives/win2012/entries/natural-kinds/>> (8 November 2014).

<sup>22</sup> Hacking, 'Kinds', pp. 291-93; Ian Hacking, 'Natural Kinds: Rosy Dawn, Scholastic Twilight', *Royal Institute of Philosophy Supplement*, 61 (2007), pp. 203-39.

## Historiography of Family Carers

### i. Nineteenth Century Psychiatry and the Family

It is important for a history of the place of the family carer in post-war mental health care to be aware of the pre-history of the carer. As medieval historian Peregrine Horden has indicated, families have been providing care for their ill relatives for centuries, and long before the emergence of the concept of 'community care.'<sup>23</sup> Fortunately, the place of the family within the history of psychiatry has been extensively researched by historians of the nineteenth century. Similarly to this thesis, some of these historians have brought their examinations of family care-givers to the fore, leaving the institution a secondary place in their analysis. These researchers have considered relationships between relatives, inmates, and medical professionals, and the 'use' of institutions by relatives. Most of this work has centred on the history of insanity, but some scholars have also begun to examine the relationship between mental deficiency and the family. In contrast, there has been a lack of scholarship on the history of family care-givers, particularly in the mental health care context, in the post-war years.

Theories of the hereditary cause of mental illness and mental deficiency prevalent in the nineteenth century cast the family as a cause, rather than a solution, to mental illness.<sup>24</sup> Despite this, a family-like environment was sanctioned as the 'ideal' institutional model by the end of the century, as typified by the

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<sup>23</sup> Horden, 'Household Care', p. 22.

<sup>24</sup> Mathew Thomson, 'Disability, Psychiatry, and Eugenics', in Alison Bashford and Philippa Levine, *The Oxford Handbook of the History of Eugenics* (Oxford, 2010), p. 117.

Quaker asylum established at The Retreat in York in 1796.<sup>25</sup> In reality, however, by the late-nineteenth-century asylum populations had vastly expanded and institutions moved further and further away from the family-like environment that epitomised The Retreat. Whereas historians of the nineteenth-century study a period when institutions were expanding, this thesis examines the period when these institutions were in retreat.

However, historians of nineteenth-century psychiatry have moved beyond this narrative of mass institutionalisation, to capture the relationship between families and psychiatry during the period. Indeed, many scholars have substantively challenged the argument of sociologist Andrew Scull that whilst families were key care-givers throughout the eighteenth century, by the nineteenth century mass institutionalisation had usurped the role of families.<sup>26</sup> Critics of Scull have nuanced the idea of mass confinement. In doing so, they have benefited from a rich source base of institutional records. These records, accessible because they lie outside the bounds of the one-hundred year rule, provide historians with a window on the interactions between relatives and the asylum. Much of the resultant literature has examined the agency of family members, including their 'use' of institutions.<sup>27</sup>

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<sup>25</sup> Andrew Scull, *Social Order/Mental Disorder. Anglo-American Psychiatry in Perspective* (London, 1989), pp. 221-25.

<sup>26</sup> Scull, *Social Order*, p. 213; Andrew Scull, *Museums of Madness: The Social Organisation of Insanity in Nineteenth Century England* (London, 1979), pp. 215-16. Andrew Scull's work drew upon philosopher Michel Foucault's argument that the nineteenth century was a time of institutional, rather than familial, care of the insane: Michel Foucault, *Madness and Civilization: A History of Insanity in the Age of Reason* (London and New York, 2001), p. 59, p. 217, p. 222.

<sup>27</sup> Hilary Marland, 'At Home with Puerperal Mania: The Domestic Treatment of the Insanity of Childbirth in the Nineteenth Century', Peter Bartlett and David Wright (eds), *Outside the Walls of the Asylum: The History of Community Care, 1750-2000* (London and New Brunswick, 1999), p. 52, p. 64; Scull, *Museums*, pp. 215-16; Scull, *Social Order*, p. 213; John K. Walton, 'Casting Out and Bringing Back in Victorian England: Pauper Lunatics, 1840-70', in W.F. Bynum, Roy Porter and Michael Shepherd (eds), *The Anatomy of Madness: Essays in the History of Psychiatry, Vol. 2: Institutions and Society* (London, 1985), p. 141; David Wright, 'Getting Out of the Asylum. Understanding the Confinement of the Insane in the Nineteenth Century', *Social History of Medicine*, 10 (1997), pp.



This revisionist literature has examined familial relationships to suggest that some families struggled to cope with insane relatives at home, especially when the condition of the mentally ill relative worsened. Hilary Marland, examining the British context, and Catharine Coleborne, focusing on the Australian experience, have examined the strain placed on familial relationships by mental illness, which could contribute to what was then known as 'domestic troubles'.<sup>28</sup> Meanwhile, Charlotte Mackenzie has asserted that families sought the admission of their relatives to an asylum when their behaviour became unmanageable.<sup>29</sup> Marjorie Levine-Clark has argued that women's insanity was often closely associated with family relationships and Hilary Marland has explained that 'the family was seen as key to the patient's misfortune and disorder in many ways', for instance with husbands often blamed for their wife's condition.<sup>30</sup>

Contrary to Scull's argument that the asylum became the 'sole officially approved response' to insanity in the nineteenth century, others, including Wright and Bartlett, have argued that 'the household remained an important locus of care for the insane' throughout the modern period.<sup>31</sup> Wright has asserted that 'the

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137-55; David Wright, 'The Certification of Insanity in Nineteenth-Century England and Wales', *History of Psychiatry*, 9 (September 1998), p. 285.

<sup>28</sup> Catharine Coleborne, *Madness in the Family: Insanity and Institutions in the Australasian Colonial World, 1860-1914* (Basingstoke, 2006), p. 77; Hilary Marland, *Dangerous Motherhood: Insanity and Childbirth in Victorian Britain* (Basingstoke, 2004), p. 158.

<sup>29</sup> Charlotte Mackenzie, 'Social Factors in the Admission, Discharge and Continuing Stay of Patients in Ticehurst Asylum, 1845-1917' in W.F. Bynum, Roy Porter and Michael Shepherd (eds), *The Anatomy of Madness: Essays in the History of Psychiatry, Vol. 2: Institutions and Society* (London, 1985), pp. 152-53, p. 159, p. 161.

<sup>30</sup> Marjorie Levine-Clark, 'Dysfunctional Domesticity: Female Insanity and Family Relationships Among the West Riding Poor in the Mid-Nineteenth Century', *Journal of Family History*, 25:3 (2000), pp. 341-43; Marland, 'At Home', p. 52, p. 60, pp. 63-4; Marland, *Dangerous Motherhood*, p. 158.

<sup>31</sup> Peter Bartlett and David Wright, 'Community Care and its Antecedents', in Bartlett and Wright (eds), *Outside the Walls*, p. 3-4, pp. 8-9, pp. 14-16; Marland, 'At Home', p. 52, p. 64; Scull, *Social Order*, p. 120, p. 216; Wright, 'Getting Out', p. 147.

testimony of the family' had an important role in the asylum admissions process.<sup>32</sup> Directly contesting Scull's argument, Walton has argued that families were actively engaged in 'casting out and bringing back' their relatives from asylums in response to family breakdown.<sup>33</sup> Wright has suggested that asylums, especially in industrial areas, also acted as a temporary solution for families economically unable to support their insane relative.<sup>34</sup> Peter Bartlett's research supports this argument by outlining how lunatics' families approached poor law officials to instigate the admissions process for their relative.<sup>35</sup> Peter Bartlett and Coleborne have respectively argued that an understanding of the system and a shared lay language of insanity empowered relatives.<sup>36</sup> Indeed, historian Akihito Suzuki has analysed the doctor-patient-family relationship to assert that family members had a degree of agency and influence when discussing the treatment of their relatives with psychiatrists.<sup>37</sup> Similarly, in this thesis, I argue that families were portrayed as both pathological and therapeutic in the post-war- era, and as the period progressed the well-being of caring relatives became an increasing concern of the state. However, with deinstitutionalisation in the post-war period, families did not always have the option to seek the admission of their relative to an institution at times when they were struggling to cope.

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<sup>32</sup> Wright, 'The Certification', p. 285.

<sup>33</sup> John K. Walton, 'Casting Out', pp. 140-1; Wright, 'Getting Out', p. 142.

<sup>34</sup> Wright, 'Getting Out', pp. 137, pp. 142-44, p. 149, p. 151.

<sup>35</sup> Peter Bartlett, *The Poor Law of Lunacy: The Administration of Pauper Lunatics in mid-Nineteenth-Century England* (London, 1999), p. 48.

<sup>36</sup> Bartlett, *Lunacy*, p. 48; Coleborne, *Madness*, pp. 143-52.

<sup>37</sup> Akihito Suzuki, 'Framing Psychiatric Subjectivity: Doctor, Patient and Record-Keeping at Bethlam in the Nineteenth Century', in Bill Forsythe and Joseph Melling (eds), *Insanity, Institutions, and Society, 1800-1914: A Social History of Madness in Comparative Perspective* (London, 1999), pp. 125-29, p. 131; Akihito Suzuki, *Madness at Home: The Psychiatrist, the Patient and the Family in England, 1820-1860* (Berkeley, 2006), pp. 65-66.

This scholarship on the history of nineteenth-century psychiatry has implications for this thesis in terms of what changes the explicit government policy of community care made to the role of families in post-war mental health care. To what extent did the relationship between families and psychiatry change, in terms of agency and use of services, once deinstitutionalisation began to take place? This work on the nineteenth century provides evidence for my study that there was a pre-history of family carers for the mentally ill before the term 'carer' itself emerged. However, I also demonstrate that the post-war case differs from that of the nineteenth century, because along with the policy of community care, came a stronger rhetoric of the expectation for relatives to provide care, and a fear that deinstitutionalisation would mean that mental hospitals would no longer be able to function as a solution for families during times when they were unable to cope.

Until relatively recently, the history of mental deficiency in the nineteenth century attracted far less attention than the history of the mentally ill. However, since the 1990s this situation has transformed. Work such as David Wright's indicates that lunacy and idiocy were closely linked.<sup>38</sup> Yet, this work also highlights the shift from optimism about educability in the first half of the nineteenth century to increasing pessimism about the hereditary nature of mental deficiency in the early nineteenth century. As Deborah Cohen has recently demonstrated, this had important implications for the position of the family in relation to care. Mental deficiency, she argues, moved from being something that families were happy to be openly involved in addressing during the Victorian era, to something that had to be

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<sup>38</sup> David Wright, *Mental Disability in Victorian England: The Earlswood Asylum, 1847-1901* (Oxford, 2001), pp. 9-10.

hidden away.<sup>39</sup> Her work argues that during the early twentieth century the role of the family in the care of relatives with mental deficiency was in retreat, because of the shame such a relative could cast on the family. However, Cohen states that during the post-war years, 'at the height of institutionalisation' many families kept mentally handicapped relatives at home. She argues that this was in part because some parents from the 1940s onwards wanted to keep their child at home.<sup>40</sup> However, as I argue in this thesis, long waiting lists for institutions and moves towards the closure of long-stay institutions meant that families often did not have any choice but to care for their child at home after the Second World War. Whilst Cohen makes a compelling argument for the history of the familial care of children with mental deficiency in the nineteenth century, she does not extensively address the post-war history of this phenomenon.

## **ii. Destabilising the History of Community Care**

During the post-war years, family care-givers for relatives with a mental illness or learning disability became increasingly acknowledged. In this thesis I argue that the government policy of community care, adopted in the early 1960s, played a significant role in the increased awareness of the role of family care-givers in mental health care. In both rhetoric and reality, care *in* the community often meant care *by* the family.<sup>41</sup> In this context family care-givers attracted considerable

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<sup>39</sup> Deborah Cohen, *Family Secrets: Shame and Privacy in Modern Britain* (Oxford, 2013), pp. 87-123.

<sup>40</sup> *Ibid.*, pp. 111-12.

<sup>41</sup> David Skidmore, *The Ideology of Community Care* (London, 1994), p. xii.

attention from social-policy makers, social researchers, the media, and parent organisations.

Whilst this thesis is not about the history of community care as such, it engages with, and destabilises, the established historiography of community care in the post-war period. The history of the family carer for mental illness and mental handicap can make an important contribution to our historical understanding of community care. The importance of the family carer to community care provision was acknowledged in the 1989 white paper *Caring for People: Community Care in the Next Decade and Beyond*: 'the reality is that most care is provided by family, friends and neighbours.'<sup>42</sup> The traditional history of community care is restrictive to historians because it provides a rigid framework. The history of the emergence of the carer, told in this thesis, begins to open up and nuance the history of community care.

Although greatly contested and frequently referred to as an empty phrase by contemporaries, the historical study of community care has thus far been predominantly concerned with fleshing out the established narrative history of the passage from an era of institutionalisation to one of deinstitutionalisation and community care.<sup>43</sup> This process is often considered to be a distinct historical event said to have taken around forty years and to have begun with the Mental Health Act of 1959 and Minister of Health Enoch Powell's, now infamous, 1961 Water

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<sup>42</sup> DHSS, *Caring for People*, p. 9.

<sup>43</sup> For example, see: WL, *The Expanding Field of Mental Health in England and Wales, 50 Years of Progress, 1918-1968*, MS.7913/30, J.E. Westmoreland, *The Development of Community Care and the Role of the Mental Health Officer* (1968), p. 2; Willmott, *Social Networks*, p. 5.

Tower Speech.<sup>44</sup> The, now well-established, narrative of institutionalisation to deinstitutionalisation and then to community care was first posited by sociologist Kathleen Jones during the 1960s and 1970s.<sup>45</sup> Jones asserted that that the policy emerged in response to criticisms of institutional psychiatric care.<sup>46</sup> As will be addressed in this thesis, however, community care has a longer history; indeed this is hinted at by the fact that the 1959 Mental Health Act did not signal an explicit move towards community care, despite it often being cited as a pivotal moment in the history of community care.<sup>47</sup>

The sociologists and social policy academics who revised Jones' initial thesis, argued that the forces behind and shaping the move from institutional to community-based provision were more varied than she had suggested. In particular, they drew attention to economic and therapeutic causes.<sup>48</sup> Although this revisionist work has nuanced Jones' argument, these academics have continued to draw heavily upon the framework of institution-deinstitutionalisation-community care, in examining the short-falls of community care policies. The framework itself

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<sup>44</sup> A case for the importance of the 1959 Mental Health Act and the 1969 Water Tower speech is included in: Hugh L. Freeman, 'The General Hospital and Mental Health Care: A British Perspective', *The Milbank Quarterly*, 73:4 (1995), pp. 657-58.

<sup>45</sup> Kathleen Jones, *A History of the Mental Health Services* (London, 1972); Kathleen Jones, *Mental Health and Social Policy, 1845-1959* (London, 1960). See also: Kathleen Jones, *Asylums and After: A Revised History of the Mental Health Services from the early 18th Century to the 1990s* (London, 1993).

<sup>46</sup> Jones, *A History*, pp. xi-xiii; Jones, *Mental Health*, pp. 178-203.

<sup>47</sup> John Welshman, 'Rhetoric and Reality: Community Care in England and Wales, 1948-74', in Peter Bartlett and David Wright (eds), *Outside the Walls of the Asylum: The History of Community Care, 1750-2000* (London and New Brunswick, 1999), pp. 210-11.

<sup>48</sup> Sociologist Andrew Scull critiqued Jones by arguing that a policy of community care was adopted primarily as a cheaper alternative to institutional care, as drug therapies were cheaper than institutional care. See: Andrew Scull, *Decarceration: Community Treatment and the Deviant – A Radical View* (2nd edn, Cambridge, 1984), pp. 135-53. Sociologist Joan Busfield has challenged Scull's thesis on the basis that psychotropic drugs were not introduced until after mental hospital populations went into decline and that Scull did not consider the cost of the introduction for community services for acute mental illnesses: Joan Busfield, *Managing Madness: Changing Ideas and Practices* (London, 1986), pp. 236-40.

requires further historical interrogation. In this thesis I begin to address relevant actors who were omitted from traditional narrative historical accounts of community care, in this case family carers and people with learning disabilities.

Policy studies academic Sarah Payne has revised Jones' thesis further by beginning to outline the failures of community care, from an increase in homelessness and violence to the 'revolving door' of short-term admissions to hospitals, with overstretched services and limited acute beds.<sup>49</sup> Indeed, whilst the peak of mental hospital populations in England and Wales was 148,100 in 1954, since then the number of patients being admitted on a short-term basis to acute psychiatry in-patient units has increased; a phenomenon which is often referred to as the revolving door of admissions.<sup>50</sup> Payne also, helpfully, defines community care in a broader sense than her predecessors, as: 'care delivered by a range of professionals and funded from a range of sources', with responsibility for mental health care provision being split between the NHS and local authorities.<sup>51</sup> However, even Payne does not fully unpack the meaning of 'community care'.

Sociologists and social policy academics, then, have frequently employed the term community care as though it had a fixed meaning and referred to a well-established historical narrative. I contend that by examining community care as both uncertain and complex richer insights can be offered to historians. From the outset (assuming the move began in the late 1950s, and I would argue that it

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<sup>49</sup> Sarah Payne, 'Outside the Walls of the Asylum? Psychiatric Treatment in the 1980s and 1990s', in Bartlett and Wright, *Outside the Walls*, pp. 244-45, p. 248.

<sup>50</sup> Peter Barham, 'From the Asylum to the Community: The Mental Patient in Postwar Britain', in Marijke Gijswijt-Hofstra and Roy Porter (eds), *Cultures of Psychiatry and Mental Health Care in Postwar Britain and The Netherlands* (Amsterdam, 1998), p. 221.

<sup>51</sup> Hugh L. Freeman, 'The General Hospital and Mental Health Care: A British Perspective', *The Milbank Quarterly*, 73:4 (1995), p. 663; Payne, 'Outside', p. 250; David Skidmore, *The Ideology*, p. 106.

occurred much earlier), community care was considered by some contemporaries to mean very little in reality and sparked considerable debate and deliberation.<sup>52</sup> Aside from favouring a move away from care in residential institutional settings, community care had different meanings to different people, not least because of a lack of consensus over what constituted 'community' and 'care'.<sup>53</sup>

However, some sociologists have begun to critically examine the meaning, or lack of meaning, of the term community care. David Skidmore has stated that there is no one definition of community, whilst Anthea Symonds and Anne Kelly have proposed three key definitions of community care: care *in* the community, care *by* the community; and care *for* the community.<sup>54</sup> Symonds goes on to explain that the 'concept of "community" occupies two parallel realities', the "'social lived reality'", and the "'dream" world of community life.' Symonds argues that these two realities are very different.<sup>55</sup> The ambiguities surrounding the notion of 'community' continued in the 1970s and 1980s. Indeed, in 1987 Conservative Prime Minister Margaret Thatcher declared that there was 'no such thing as society' there were only 'individuals and families'.<sup>56</sup> Paradoxically, Thatcherism and the rise of the individual occurred at the same time as community care initiatives were on the rise.<sup>57</sup>

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<sup>52</sup> Roy Porter, 'Two Cheers for Psychiatry! The Social History of Mental Disorder in Twentieth Century Britain' in Hugh Freeman and German Berrios (eds), *150 Years of Psychiatry: The Aftermath* (London, 1996), p. 401; Skidmore, *Community Care*, p. 106; Willmott, *Social Networks*, p. 5.

<sup>53</sup> Horden, 'Household Care', pp. 35-36; Willmott, *Social Networks*, p. 5.

<sup>54</sup> Skidmore, *The Ideology* (London, 1994), p. 1; Anthea Symonds and Anne Kelly, 'Introduction', in Anthea Symonds and Anne Kelly (eds), *The Social Construction of Community Care* (Basingstoke, 1998), pp. 3-6.

<sup>55</sup> Symonds, 'Social Construction and the Concept of Community', in Symonds and Kelly, *Social Construction*, pp. 12-14.

<sup>56</sup> Margaret Thatcher Foundation, 'Margaret Thatcher Interview for Women's Own', 23 September 1987. <[www.margaretthatcher.org/document/106689](http://www.margaretthatcher.org/document/106689)> (9 December 2014).

<sup>57</sup> Ben Jackson and Robert Saunders (eds), *Making Thatcher's Britain* (Cambridge, 2012).



In a 2011 special edition of *History of Psychiatry*, Volker Hess and Benôit Majerus, along with Greg Eghigian, called for historians to begin writing the non-institutional history of twentieth-century psychiatry. Hess, Majerus, and Eghigian argued that, unlike for the late-nineteenth and early-twentieth century, an interpretive framework for the post-war period still needs to be devised.<sup>58</sup> However, historians of twentieth-century British psychiatry have in fact been looking beyond institutional contexts for the past two decades.

Historians examining the first half of the twentieth century have begun to look beyond the institution to the family and the community. Mathew Thomson has argued that by examining the links between voluntarism and the state it is possible to find examples of experiments into community care for mental deficiency occurring as early as the 1920s and 1930s.<sup>59</sup> Similarly to historians of the nineteenth century, John Welshman has explained that the 'mixed economy' of mental health care, which included familial care within the community, pre-dated a formal policy of community care.<sup>60</sup> Meanwhile, Stephen Soanes has used the case study of convalescence to demonstrate an association between psychiatry and community care from the start of the twentieth century.<sup>61</sup>

Although a new field which requires more extensive study, scholars have also started to extend the examination of the history of community care and

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<sup>58</sup> Volker Hess and Benôit Majerus, 'Writing the History of Psychiatry in the 20<sup>th</sup> Century', *History of Psychiatry*, 22 (2011), pp. 139-45; Greg Eghigian, 'Deinstitutionalising the History of Contemporary Psychiatry', *History of Psychiatry*, 22 (2011), pp. 201-14.

<sup>59</sup> Thomson, *Mental Deficiency*, pp.149-79; Mathew Thomson, 'Sterilization, Segregation and Community Care: Ideology and Solutions to the Problem of Mental Deficiency in Inter-War London', *History of Psychiatry*, 3 (1992), p. 490. See also: Jan Walmsley, Dorothy Atkinson, and Sheena Rolph, 'Community Care and Mental Deficiency 1913-1945', in Bartlett and Wright, *Outside the Walls*, pp. 181-203.

<sup>60</sup> Welshman, 'Rhetoric', pp. 204-7.

<sup>61</sup> Stephen Soanes, 'Rest and Restitution: Convalescence and the Public Mental Hospital in England, 1919-39', (PhD thesis, University of Warwick, 2011), pp. 281-82.

mental health care to the post-war period. Indeed, a significant contribution was made to this field in 1999 with the publication of the edited collection, *Outside the Walls of the Asylum*.<sup>62</sup> Contributions to this volume argued that there is a long history of the family and the community being involved in the care and control of mental illness. At the same time, however, the contributors suggested that the place of the family within mental health care, although a constant phenomenon, has tended to be unstable and fluid in nature.

One reason for the fluidity of the place of the carer in post-war mental health care has been the co-existence of different schools of psychiatric thought and different 'psych' professions during the period. New approaches developed in the context of the struggle to cure mental illnesses, such as schizophrenia, in the face of the discovery that psychotropic drugs were not effective for all service-users, and in light of criticism of mass-institutionalisation. Through an examination of psychiatric social workers, historian Vicky Long has demonstrated that some professionals considered mental illness to be physical, requiring physical treatments, whilst others thought it was social and supported social models of psychological treatment.<sup>63</sup> Psychiatric social workers, along with social psychiatrists, perceived the family, and the patient's social environment, as important, and positive, factors in both treatment and care.<sup>64</sup>

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<sup>62</sup> Bartlett and Wright, *Outside the Walls*.

<sup>63</sup> Lucy Johnstone, *Users and Abusers of Psychiatry: A Critical Look at Traditional Psychiatric Practice* (London, 1989), p. 84, p. 158, p. 188; Vicky Long, "'Often there is a Good Deal to be Done, But Socially Rather Than Medically". The Psychiatric Social Worker as Social Therapist, 1945-70', *Medical History*, 55 (2011), p. 223.

<sup>64</sup> Long, 'Social Therapist', p. 229; Rhodri Hayward, 'Sadness in Camberwell: Imagining Stress and Constructing History in Postwar Britain', in David Cantor and Edmund Ramsden (eds), *Stress, Shock, and Adaptation in the Twentieth Century* (Rochester, 2014), p. 324.

Anti-psychiatry was also critical of the medical model of psychiatric diagnosis and treatment. Although often referred to as a 'movement', those that came to be thought of as part of the movement often rejected this designation, not least because the different thinkers often had different views and ideas.<sup>65</sup> The key figures of the anti-psychiatry movement in Britain were: David Cooper, Michel Foucault, Erving Goffman, R.D. Laing, and Thomas Szasz. David Cooper and R.D. Laing were particularly vocal on the role of the family in the cause and treatment of mental illness, and their views, although social in nature, opposed those propagated by social psychiatry and psychiatric social workers. Laing and Cooper considered schizophrenia to be socially constructed and caused by family members, and in particular mothers.<sup>66</sup>

In the context of moves towards deinstitutionalisation, it is unsurprising that various loci of care were proposed to be ideal, including mental hospitals, community-based accommodation, acute mental health units in general hospitals, and therapeutic communities.<sup>67</sup> Historian Bonnie Evans has argued that deinstitutionalisation had another impact on mental health care. Evans has suggested that in addition to new theories related to child psychology and epidemiology, the closure of long-stay institutions, led to a changed understanding of autism in 1960s and 1970s Britain and an increase in diagnoses of the

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<sup>65</sup> Marijke Gijswijt-Hofstra, 'Introduction: Cultures of Psychiatry and Mental Health in Postwar Britain and the Netherlands', in Gijswijt-Hofstra and Porter, *Cultures of Psychiatry and Mental Health Care in Postwar Britain and The Netherlands*, p. 2.

<sup>66</sup> David Cooper, *The Death of the Family* (London, 1971), p. 9; R.D. Laing and A. Esterson, *Sanity, Madness and the Family* (2nd edn, Harmondsworth, 1970); Porter, 'Two Cheers!', pp. 401-2.

<sup>67</sup> Diana Gittins, *Madness in its Place: Narratives of Severalls Hospital, 1913-1997* (London, 1998); Porter, 'Two Cheers!', p. 400.

condition.<sup>68</sup> At a time when mental deficiency hospitals were closing, more children were being diagnosed as autistic and therefore required care in the home.

Deinstitutionalisation, the movement of patients into the community, and a growing awareness of the phenomenon of familial care-giving had an impact on public and cultural understandings, representations, and reactions to mental health care. In the 1990s historian Sander Gilman began examining visual representations of the insane.<sup>69</sup> During the same decade, the Glasgow Media Group conducted research on a variety of topics related to the media, including mental illness, considering media representations, but also audience reception.<sup>70</sup> Historian Vicky Long has considered the changing representations of mental illness, for instance by examining the dynamic between the media and stigmatisation of mental illness.<sup>71</sup> The Glasgow Media Group and Long have both considered documentary film sources as part of their research which has opened up a new area of study for historians interested in the relationship between mental illness and media representations. As this thesis demonstrates, documentary and documentary-drama representations of the care of people with mental illnesses and learning disabilities provided an opportunity for the public to become more aware of the experiences of family carers, especially in terms of familial relationships.

The history of mental health care, ethnicity, and migration has begun to be researched by historians. For example, Catherine Cox, Hilary Marland, and Sarah

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<sup>68</sup> Bonnie Evans, 'How Autism became Autism: The Radical Transformation of a Central Concept of Child Development in Britain', *History of the Human Sciences*, 26:3 (2013), pp. 3-31.

<sup>69</sup> Sander L. Gilman, *Seeing the Insane* (London, 1996).

<sup>70</sup> Greg Philo (ed.), *Media and Mental Distress* (London, 1996); Greg Philo (ed.), *Message Received: Glasgow Media Group Research, 1993-1998* (Harlow, 1998).

<sup>71</sup> Vicky Long, 'Changing Public Representations of Mental Illness in Britain 1870-1970 (PhD thesis, University of Warwick, 2004); Vicky Long, *Destigmatising Mental Illness: Professional Politics, Stigma, and Public Education in Britain, 1870-1970* (Manchester, forthcoming).

York have researched the relationship between lunacy and Irish migration to England in the nineteenth century.<sup>72</sup> Jordanna Bailkin is one of the few scholars who has examined the relationship between mental health care and migration after the Second World War.<sup>73</sup> Bailkin argues that 'the treatment of migrants was distinctly at odds with broader trends in the field of mental health in Britain', particularly in terms of the 1959 Mental Health Act, which treated migrants differently to British citizens.<sup>74</sup> Given this, and the high diagnosis of migrant populations in Britain with mental illnesses, especially schizophrenia, the relationship between mental health care, ethnicity, and migration warrants further study. Whilst researching this thesis, however, the themes of ethnicity and migration rarely came up until the late 1990s when types of carers and service-users became a prime concern for campaigners and policy makers. The evidence within the records that speak to the history of the family carer demonstrates that family care-givers were often thought of as white, British, and female.

Scholars have also begun to examine the history of learning disability in the context of community care. For example, David Wright has written a history of one particular learning disability, Down's Syndrome, which draws upon his personal experience of having a sister with the condition.<sup>75</sup> Health and social care academic Dorothy Atkinson, along with historians Mark Jackson and Jan Walmsley, have written a history of learning disability which includes archival material with people's

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<sup>72</sup> Catherine Cox, Hilary Marland, and Sarah York, 'Emaciated, Exhausted, and Excited: The Bodies and Minds of the Irish in Late Nineteenth Century Lancashire Asylums', *Journal of Social History*, 46:2 (2012), pp. 500-24. See also, Catherine Cox and Hilary Marland (eds), *Migration, Health, and Ethnicity in the Modern World* (Basingstoke, 2013).

<sup>73</sup> Jordanna Bailkin, *The Afterlife of Empire* (London, 2012), pp. 33-45.

<sup>74</sup> Bailkin, *Empire*, pp. 42-43.

<sup>75</sup> David Wright, *Downs: The History of the Disability* (Oxford: Oxford University Press, 2011).

life stories.<sup>76</sup> However, these scholars have tended to overlook the opportunity to situate the history of learning disability within the mental health care context. Whilst Thomson has considered the history of mental deficiency in relation to mental health care, his analysis focused on the inter-war period.<sup>77</sup>

An exception to this has been *Outside of the Walls*, a landmark volume which began to integrate the history of learning disability within the history of post-war psychiatry, mental health care, and community care.<sup>78</sup> However, with one exception, this volume separated the topics of mental illness and learning disability into distinct chapters with separate authors, rather than consider the, often, complex interplay between the two topics. Likewise, the collection *Disabled Children*, edited by Anne Borsay and Pamela Dale separated analysis on mental illness and learning disability into separate chapters or subsumed it within the broader analytical category of disability.<sup>79</sup> In another edited collection, *Mental Illness and Learning Disability Since 1850*, Pamela Dale and Joseph Melling employ 'mental disorder', uncritically, as an umbrella term referring to both mental illness and learning disability.<sup>80</sup> In the same volume, John Welshman begins, however, to confront the tensions and continuities between the histories of mental illness and learning disability with his study of hostels.<sup>81</sup> Further, in his contribution to *Outside*

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<sup>76</sup> Dorothy Atkinson, Mark Jackson and Jan Walmsley, *Forgotten Lives: Exploring the History of Learning Disability* (Kidderminster, 1997).

<sup>77</sup> Thomson, *Mental Deficiency*.

<sup>78</sup> Bartlett and Wright, *Outside the Walls*.

<sup>79</sup> Anne Borsay and Pamela Dale (eds), *Disabled Children: Contested Caring, 1850-1979* (London, 2012).

<sup>80</sup> Pamela Dale and Joseph Melling (eds), *Mental Illness and Learning Disability since 1850: Finding a Place for Mental Disorder in the United Kingdom* (Abingdon, 2006).

<sup>81</sup> John Welshman, 'Inside the Walls of the Hostel, 1940-74', in Dale and Melling, *Mental Illness*, p. 219.

*the Walls* Welshman examined community care policies and services for both the mentally ill and handicapped between 1948 and 1974.<sup>82</sup>

Recently, mental health survivors have begun to write about the history of mental health care from their own experience.<sup>83</sup> These accounts provide us with a retrospective history of community care based on the insights of people who experienced the process of hospital closures. This avenue of inquiry was popularised in the discipline of history by collected volumes of personal accounts of the experience of madness compiled by Dale Peterson and Roy Porter.<sup>84</sup> Whilst these histories do not directly consider the history of the family carer, they offer insight into the fact that, as Barham has stated, some service-users were 'their own main carers'.<sup>85</sup> Historian Barbara Taylor has written a memoir of her experience as a patient in Friern hospital which also serves to reassess the history of mental health care in the twentieth century.<sup>86</sup> Additionally, mental health activist and mental health survivor Peter Campbell has written about the survivor movement.<sup>87</sup> Various histories of learning disability in the twentieth century have been written to include first-hand accounts from people with learning disabilities and members of the self-advocacy movement.<sup>88</sup>

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<sup>82</sup> Welshman, 'Rhetoric', pp. 204-226.

<sup>83</sup> For example, see: Thurstine Basset and Theo Stickley (eds), *Voices of Experiences: Narratives of Mental Health Survivors* (Chichester, 2010).

<sup>84</sup> Dale Peterson (eds), *A Mad People's History of Madness* (London, 1982); Roy Porter (eds), *The Faber Book of Madness* (London, 1991).

<sup>85</sup> Barham, 'From the Asylum', p. 223.

<sup>86</sup> Barbara Taylor, 'The Demise of the Asylum in Late Twentieth-Century Britain: a Personal History', *Royal Historical Society*, 21 (2011), pp. 193-215; Barbara Taylor, *The Last Asylum: A Memoir of Madness in Our Times* (London, 2014).

<sup>87</sup> Peter Campbell, *Some Things You Should Know About User / Survivor Action* (London, 2006).

<sup>88</sup> For instance, see: Atkinson, Jackson and Walmsley, *Forgotten Lives*; S. Rolph, D. Atkinson, M. Nind, and J. Welshman (eds), *Witnesses to Change: Families, Learning Difficulties and History* (Kidderminster, 2005).

Despite this move to consider non-professional viewpoints within post-war psychiatry, the relationship between the family and community care in the post-war period has been underrepresented in existing historical accounts. For, as Skidmore has recognised, in reality care in the community meant care *by* the community and in particular care by relatives.<sup>89</sup> One of the few historians to appreciate this is John Welshman, who has argued that families were implicitly expected to become carers for mental illness following deinstitutionalisation.<sup>90</sup> However, Welshman's work takes a social policy approach and is currently limited in scope to two book chapters. What also merits more consideration from historians of mental health care is that throughout the course of the second half of the twentieth century considerations of community care had a focus much broader than simply the movement of long-stay patients from mental hospitals to the outside world, also encompassing the care of people with physical disabilities and old age care. Family carers, and community care more broadly, became increasingly important to the British welfare state in the post-war period, and this warrants further historical research and interrogation.

A focus exclusively on the history of community care does not allow historians to consider the broader context of post-war mental health care, psychiatry, and the family. For this reason, this thesis is not a history of community care per se. Indeed, the family's role in the care of those with mental illnesses and learning disabilities predates the emergence of community care policies. Nevertheless, post-revisionist accounts of the history of community care, particularly those written by Thomson and Welshman, have opened up the family

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<sup>89</sup> Skidmore, *The Ideology*, p. xii.

<sup>90</sup> Welshman, 'Rhetoric', p. 226.



carer as an avenue of historical research by beginning to destabilise the history of community care and its relationship to the family.

### **iii. Towards a History of the Family Carer**

In recent years scholars, and in particular sociologists and health and social care academics, have begun to write the history of the family carer. These accounts have focused on the themes of feminism and care, the construction of the carer via social policy, and old age. These historical accounts, however, have tended to be brief, amounting to a chapter in an edited volume, a handful of references throughout a monograph, or a journal article. A detailed historical literature on the history of informal care in the post-war period is yet to be written.

One of the main themes in the current literature on the family carer has been the acknowledgement of the complexities of the term 'carer'. As early as 1986, sociologist Peter Willmott stated that it was difficult to distinguish between informal and formal care, because 'the boundaries are both open and fluid.'<sup>91</sup> In the introduction to her 2006 book, *Hidden Carers*, health and social care academic, Joyce Cavaye considered the problems of definition inherent to the history of the family carer, and the way that literature from the 1980s and 1990s was beginning to recognise this problem.<sup>92</sup> In particular, she refers to a 1990 article by sociologists Sara Arber and Jay Ginn, who stated: 'to search for a single "ideal" dichotomous definition of a "carer" is over-ambitious and probably futile, in view of the multi-

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<sup>91</sup> Willmott, *Social Networks*, p. 5.

<sup>92</sup> Joyce Cavaye, *Hidden Carers* (Edinburgh, 2006), pp. ix-3.

faceted nature of caring.<sup>93</sup> However, carers were often assumed to be women and Arber and Ginn have stressed that 'carers' came to be a 'social group sharing a common problem and a common interest' as a result of feminist literature about female domestic labour.<sup>94</sup>

Health and social care academics Bill Bytheway and Julia Johnson reflected in their 1998 publication that 'it is perhaps difficult to appreciate that less than forty years ago, the term carer was barely in the English language and particularly difficult for those many people who perceive themselves to be carers.'<sup>95</sup> Bytheway and Johnson's social constructionist examination of the history of the carer provides a seemingly straightforward, chronological history of the emergence of the informal carer broadly defined, to include carers for people with a range of different health issues, needs, and disabilities. Bytheway and Johnson suggest that most of the changes occurred within the past forty years, which overlooks the longer term history of family care-giving and the complexities of the emergence of the term 'carer'. Whilst their contribution to the field is a helpful starting point to the study of the history of the carer, the scope of Bytheway and Johnson's analysis is limited in that they focus on a chronological account of how social policy and government-sponsored social research impacted on the construction of the carer. This top-down approach does not consider the significant influence for example of other social scientific researchers, second-wave feminists, and voluntary action.

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<sup>93</sup> Sara Arber and Jay Ginn, 'The Meaning of Informal Care: Gender and the Contribution of Elderly People', *Ageing and Society*, 10:4 (1990), p. 438.

<sup>94</sup> Arber and Ginn, 'The Meaning', p. 430.

<sup>95</sup> Bytheway and Johnson, 'The Social Construction of Carers' in Symonds and Kelly, *Social Construction*, p. 241. This chapter was reproduced in: Bill Bytheway and Julia Johnson, 'The Social Construction of Carers' in Julia Johnson and Corrine De Souza (eds), *Understanding Health and Social Care: An Introductory Reader* (2nd edn, Los Angeles and London, 2008), pp. 223-33.

Much of the existing scholarship on carers has been written with a focus on old age. For instance, Arber and Ginn focus on the informal care of the elderly. Their feminist analysis of the carer is in part a result of the care of the elderly in the post-war period often being associated with female carers. Cavaye also focuses on the history of informal care for older people, but she adopts a broader view of the factors which led to the acknowledgement of informal carers. Cavaye, along with Bytheway and Johnson, suggests that researchers and policy makers, on the one hand, and pressure groups, on the other, were responsible for the emergence of the language of informal 'care'.<sup>96</sup> Whereas Cavaye posited that these factors made the carer 'visible', Bytheway and Johnson take this point a step further than Cavaye by arguing that the 'carer' was socially constructed by the 'carers movement and policy researchers' groups.<sup>97</sup> Bytheway and Johnson argue that these interest groups, whilst making people more aware of informal carers, have 'obscured to some extent the realities of informal care-giving and, therefore, appropriate ways of supporting those who provide care in the community.'<sup>98</sup> Bytheway and Johnson, however, focus their analysis on a narrow time frame, between 1975, with the introduction of the Invalid Care Allowance, and 1995 when the Carers (Recognition and Services) was enacted.

In this thesis, I accept that the emergence of the family carer for mental health care was indeed heavily influenced by concern about care for the elderly. There is not only recent social policy literature but also research on the longer-term historical development to support such analysis. Writing on the history of old age

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<sup>96</sup> Bytheway and Johnson, 'Carers', pp. 241-53; Cavaye, *Hidden Carers*, p. 2.

<sup>97</sup> Bytheway and Johnson, 'Carers', pp.241-53; Cavaye, *Hidden Carers*, p. 2.

<sup>98</sup> Bytheway and Johnson, 'Carers', p. 253.

in Britain, Pat Thane has indicated the ongoing importance of informal care.<sup>99</sup>

However, Thane also highlighted the significance of the 1985 General Household Survey which surveyed informal care in Britain for the first time and revealed six million informal carers in Britain, in bringing the role and language of the carer for the elderly to public attention.<sup>100</sup> Despite this, Thane argues that by the late 1980s families often cared for elderly relatives with little support from local authorities.<sup>101</sup> Her history of old age therefore highlights an important role for the informal carer across time, but an ongoing struggle for recognition and adequate support.

In this work on the informal care of the elderly, Thane also considered international variations. The findings are intriguing. On the one hand, she found that, despite a vastly different level of state welfare in Britain compared to the United States of America, the instance of familial care for old people was similar. On the other hand, at first sight somewhat counter-intuitively, the data indicated that 'levels of family support were higher in West Germany, where welfare services were strong, than in the USA where they were weaker.'<sup>102</sup> Part of the answer to this conundrum can be found in the work of Caroline Glendinning and Gerhard Igl, who compared long-term care for old age in Germany and the United Kingdom (UK). As Glendinning and Igl pointed out: 'the UK is one of the few countries where informal carers have direct entitlements to financial and other forms of supporting their own right, rather than indirectly through benefit entitlement of an older person who is receiving care.' The German system is one where there is a 'greater emphasis on

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<sup>99</sup> Pat Thane, *Old Age in English History: Past Experiences, Present Issues* (Oxford, 2000); Pat Thane, 'Memorandum Submitted to the House of Commons' Health Committee Inquiry: Social Care', *History and Policy* (October 2009): [http://www.historyandpolicy.org/docs/thane\\_social\\_care.pdf](http://www.historyandpolicy.org/docs/thane_social_care.pdf).

<sup>100</sup> Bytheway and Johnson, 'Carers', pp. 245-47; Thane, *Old Age*, p. 430.

<sup>101</sup> Thane, *Old Age*, p. 429.

<sup>102</sup> *Ibid.*, pp. 430-33.

supporting their role as carers and less on recognising their own economic independence.<sup>103</sup> Such research points to the complexity of the relationship between systems of welfare, law, and family care. It also indicates that the UK may be an exceptional case study in the history of the emergence of the family carer, especially in terms of state support directly to the carer. Building on this work of the elderly, this thesis will examine whether such a route was also characteristic of the development in the field of mental health care, and it will attempt to explain why this was the case.

The concern over an ageing population and responses to the informal care of old people has a key position in the history of the carer. However, the place of the carer in mental health care in the post-war period is also beginning to attract scholarly attention. Thus far this literature has tended to examine the social policy related to the informal care of the mentally ill.<sup>104</sup> For instance, in the second edition of *Mental Health Policy in Britain* (2001), sociologists Anne Rogers and David Pilgrim include professionals, including politicians, service-users, and carers in their history of the main stakeholders in post-war mental health care.<sup>105</sup> Rogers and Pilgrim stress that 'informal care in the area of mental health is not the same as that associated with carers of people with physical illness or disabilities or of children or elderly people.' For instance, they suggest that, informal care may 'aggravate the mental health of both parties'. As such, they note that 'the needs of relatives should

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<sup>103</sup> Caroline Glendinning and Gerhard Igl, 'Long-term Care in Germany and the UK', in Alan Walker and Gerhard Naegele (eds), *Social Policy in Ageing Societies: Britain and Germany Compared* (Basingstoke, 2009), pp. 202-33.

<sup>104</sup> For an early examination of the relationship between informal care and social policy, from 1986, see: Willmott, *Social Networks*.

<sup>105</sup> Anne Rogers and David Pilgrim, *Mental Health Policy in Britain* (2nd edn, Basingstoke, 2001), p. 221.

have separate consideration within mental health policy and provision', which they indicate was an outcome of the 1994 Mental Health Foundation inquiry and the 1999 National Strategy for Carers.<sup>106</sup> However, Pilgrim and Rogers do not give an in-depth analysis of the history of informal care in the mental health context.

Primary care academic Helen Lester and health and social care academic Jon Glasby have considered how the place of the carer in mental health care was still in flux in 1990s and 2000s Britain. They argue that the definition of 'the carer' continues to be problematic today for four reasons. Firstly, 'informal care' can be perceived as patronising and does not 'reflect the central importance of carers within health and social services'. Secondly, the term has connotations of burden, but can be a positive experience. The term also does not account for the experiences of those being cared for. Thirdly, as socially constructed terms, 'service-user' and 'carer' do not reflect real lived experience. And fourthly, people do not necessarily see themselves as carers. Lester and Glasby also argue that even the 1995 Carers (Recognition and Services) Act did little to recognise carers and set up better links between carers and service providers.<sup>107</sup> However, as this thesis will suggest, the language which emerged to talk about caring and the place of the carer in mental health care in the 1980s was also applicable to describe the phenomenon of family care-giving from the mid-1940s onwards. By focusing too heavily on language, Lester and Glasby do not consider the longer-term emergence on the family carer. However, the change in language is significant in its own right as it can

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<sup>106</sup> Rogers and Pilgrim, *Policy*, p.112, p. 121-22, pp. 164-65, p. 221; Hilary Arksey and Caroline Glendinning provide a helpful overview of social policy and the needs of carers in: Hilary Arksey and Caroline Glendinning, 'Informal Welfare', in Pete Alcock, Margaret May, and Sharon Wright (eds), *The Student's Companion to Social Policy* (4th edn, Chichester, 2012), pp. 234-40.

<sup>107</sup> Lester and Glasby, *Policy*, p. 208.

tell us about lived experience as carers, and other interested parties, worked to negotiate, and in some instances reinforce, challenge, or resist the label of 'carer'. By doing so these groups disseminated information and narrative accounts on what it was like to be a carer. This dialogue and lobbying changed what it meant to be a carer. So, it is necessary to look both at the language used in debates and discussions, but also to look at the rhetoric and realities behind and beyond this terminology.

Lester and Glasby, and the other academics who have written on the history of the carer, do not consider another influence on the changing definition of the category of the carer, that of the related shifting, and permeable, boundary between mental illness and learning disability. In fact, as my work will show, the family carer emerged in a very real sense in the 1940s in the context of mental handicap. Whilst these carers were referred to as parents or mothers rather than carers, they provided long-term care for their children above and beyond that normally expected in a family. As this indicates, and as I will argue, we do therefore need a history that goes beyond the emergence of the term and which looks back at least to the aftermath of the Second World War. In particular, we need to recognise the relationship between the coming to the fore of the carer in this period and the parallel history of community care. This relationship is neglected in the existing historiography and is at the heart of this thesis. I now turn to other historiographies of post-war Britain to consider existing scholarship on the following distinctive characteristics of the period: the emergence of the welfare state, demographic and structural change to the family, new disciplines, and voluntary action.

## Post-War British Historiography

### i. The Welfare State

The welfare state has been central to many landmark studies of post-war British history.<sup>108</sup> Indeed, owing to the establishment of the welfare state, Britain had a distinct experience compared to other nations and was in many respects defined by its social security and health care systems. The emergence of the family carer in England and Wales was influenced by the welfare state, not least because of social security benefits being paid to family care-givers from the mid-1970s onwards. The foundations of the post-war social security system were laid by the Beveridge Report in 1942, which aimed to combat the 'five giants' of Want, Disease, Ignorance, Squalor, and Idleness. However, some historians have argued the case for a longer-term evolution of the welfare state. These historians, including James Cronin, Jose Harris, and Paul Johnson, have argued that the emergence of the welfare state was due to a range of long-term factors and mixed with short-term causes.<sup>109</sup>

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<sup>108</sup> For an alternative view, see the work of historian David Edgerton who has resisted the notion of Britain as a distinctly welfare state in the second half of the twentieth century: David Edgerton, *Warfare State: Britain, 1920-1970* (Cambridge, 2006).

<sup>109</sup> James Cronin, 'The British State and the Structure of Political Opportunity', *Journal of British Studies*, 27 (1988), pp. 199-231; James Cronin, *The Politics of State Expansion: War, State, and Society in Twentieth-Century Britain* (London, 1991); Jose Harris, 'Society and State in Twentieth Century Britain', in F.M.L. Thompson (ed.), *Cambridge Social History of Britain, Vol. 3, Social Agencies and Institutions* (Cambridge, 1993), pp. 63-118; Paul Johnson, 'The Role of the State in Twentieth Century Britain', in Paul Johnson (ed.), *Twentieth-Century Britain: Economic, Social and Cultural Change*, (London, 1994), pp. 476-91. See also, Thomson, *Mental Deficiency*, pp. 270-93.



The blueprint provided by Beveridge was based on an assumption of universal entitlement, but also universal (male) employment, and established a new relationship between the state and British citizens.<sup>110</sup> Although not laid out in any substantive way in the Beveridge Report, the National Health Acts, beginning in 1948, set in motion the beginning of the National Health Service (NHS).<sup>111</sup> Official historian of the NHS, Charles Webster, has argued that the development of the NHS was often dictated and constricted by the professional interests of medical professionals.<sup>112</sup>

Webster has also argued that from the outset of the NHS there was an intent to move away from long-term hospital care for the mentally ill. This was based on the notion that primary care would be complemented by community care, which would serve the mentally ill and the elderly.<sup>113</sup> The NHS intended to unify the health care system, which would incorporate mental health care services, and the 1959 Mental Health Act sought for mental illnesses to be treated in the same way as physical illnesses. Historians have argued, however, that throughout the post-war years both psychiatry and mental health care have been Cinderellas within the British social welfare system.<sup>114</sup>

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<sup>110</sup> Peter Clarke, *Hope and Glory: Britain 1900-2000* (2nd edn, London, 2004), pp. 213-14, pp. 221-22.

<sup>111</sup> *Ibid.*, pp. 222-24.

<sup>112</sup> Charles Webster, 'Conflict and Consensus: Explaining the British Health Service', *Twentieth Century British History*, 1 (1990), pp. 115-51.

<sup>113</sup> Charles Webster, *The National Health Service: A Political History* (Oxford, 1998), pp. 53-54.

<sup>114</sup> The notion of psychiatry and mental health care as Cinderella's within medicine and the social welfare landscape in Britain is a common trope within histories of British psychiatry in the twentieth century. For example, see: Porter, 'Two Cheers', p. 400.

This trope was also employed, and interrogated by contemporaries, for instance: C. Hubert Bond, 'The Position of Psychiatry and the Role of General Hospitals in its Improvement: The Introductory Address delivered at the Opening of the Winter Session, 1914-15, at the Middlesex Hospital on October 1st, 1914', *Journal of Mental Science*, 61, pp. 1-17.

In the 1950s, sociologist Thomas Humphrey Marshall and social administration academic Richard Titmuss argued the case for a new relationship between the British state and its citizens following the emergence of the welfare state and a new 'social citizenship'.<sup>115</sup> Marshall and Titmuss' theses were subsequently challenged on the grounds that national citizenship went into decline with changes to work, war, and reproduction patterns.<sup>116</sup> Not all British citizens were able to exercise the social rights and democratic freedoms of 'social citizenship'.<sup>117</sup> Regardless of whether the relationship between the state and citizen changed following the Second World War and whether the welfare state was initially built upon a consensus, historians have argued that by the 1950s and 1960s the post-war settlement was beginning to destabilise.<sup>118</sup> Indeed, historian Rodney Lowe has argued that the 1970s was a time of crisis for the welfare state.<sup>119</sup> In a similar vein, historian James Vernon has argued that the central historical problem of the twentieth century was the brevity of social democracy.<sup>120</sup>

One of the reasons for the destabilisation of the post-war settlement was socio-economic, and cultural, shifts and changes within Britain. These changes

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<sup>115</sup> T.H. Marshall, *Citizenship and Social Class, and Other Essays* (Cambridge, 1950); Richard Titmuss, *Problems of Social Policy* (London, 1950).

<sup>116</sup> James Vernon, 'The Local, the Imperial, and the Global: Repositioning Twentieth Century Britain and the Brief Life of its Social Democracy', *Twentieth Century British History*, 21:3 (2010), p. 404-18.

<sup>117</sup> Ross McKibbin, *Classes and Cultures in England, 1918-1951* (Oxford, 1994), pp. 553-56; Thomson, *Mental Deficiency*, pp. 270-93; Bryan S. Turner, 'The Erosion of Citizenship', *British Journal of Sociology*, 52:2 (June 2001), pp. 189-209.

<sup>118</sup> Brad Beaven and John Griffiths, 'Creating the Exemplary Citizen: The Changing Notion of Citizenship in Britain, 1870-1939', *Contemporary British History*, 22 (2008), 203-25; Geoffrey Finlayson, 'A Moving Frontier: Voluntarism and the State in British Social Welfare, 1911-1949', *Twentieth Century British History*, 1 (1990), pp. 183-206; Jose Harris, 'Political Thought and the Welfare State, 1870-1940: An Intellectual Framework for British Social Policy', *Past & Present*, 135 (1992), pp. 116-41; Mathew Thomson, *Lost Freedom: The Landscape of the Child and the British Post-War Settlement* (Oxford, 2013), pp. 10-12.

<sup>119</sup> Rodney Lowe, *The Welfare State in Britain since 1945* (2nd edn, Basingstoke, 1995), pp. 301-29.

<sup>120</sup> James Vernon, 'The Local, the Imperial, and the Global: Repositioning Twentieth Century Britain and the Brief Life of its Social Democracy', *Twentieth Century British History*, 21:3 (2010), p. 404-18.

became a particular concern during the 1960s and 1970s during the era of the so-called 'permissive society.' Concerns over moral degradation emerged out of increased divorce rates, declining church attendance, liberal and progressive legislation, and concerns over youth and counterculture.<sup>121</sup> Concurrently, fears that affluence was leading to the breakdown of communities, along with anxiety about structural changes to the institution of the family, and the rediscovery of poverty, led left- and right-wing politicians to become concerned about the family. Social movements, including second-wave feminism, emerged out of this context, which meant that these issues were debated in detail from various view points.

This thesis contributes to the history of the welfare state by using the example of the family carer as a case study for changes to, challenges to, and the destabilisation of, the welfare state in the post-war period. In particular, the case study of the family carer provides insight into challenges to the male breadwinner model which was a basis of the welfare state when originally conceived and the ways in which British citizens feel a sense of entitlement for the state to provide welfare services.

## **ii. Voluntary Action**

This thesis will contribute to the history of voluntary action by providing histories of two large and influential parent and carer groups, the National Schizophrenia Fellowship and Mencap. Also, I demonstrate that the collectivisation of a group of

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<sup>121</sup> For an overview of the 'permissive society' see: Arthur Marwick, *The Sixties: Cultural Revolution in Britain, France, Italy, and the United States, c. 1958-1974* (Oxford, 1998); Marcus Collins (ed.), *The Permissive Society and its Enemies: Sixties British Culture* (London, 2007).

people, in this case the relatives of people with mental illness and learning disability, could be hugely influential in understandings of, emotional reactions to, representations of, and political interest in, a particular issue or type of person.

Not all families were passive in response to the uncertainties surrounding the place of citizens within the welfare state. Indeed, as I have already argued, despite the emergence of the welfare state, there continued to be a mixed economy of care which included care provided by families.<sup>122</sup> During the post-war years a range of voluntary organisations, and parent and carer groups, emerged which were related to the mental health field. Significantly, parent groups for learning disability, or mental handicap, emerged earlier than those for mental illness, which raises questions in terms of the conceptualisation and familial experiences of mental illness and mental disability in post-war Britain. Some historians have already pointed to the significance of the simultaneity of concerns over the family and the emergence of parent and carer organisations, although this requires further research.<sup>123</sup> Historian Frank Prochaska has noted that by 1988 that there 'were more than a million carers of aged and disabled relatives without state or charitable assistance', and as such it is important not to assume that all families were members of, or helped by, these organisations.<sup>124</sup>

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<sup>122</sup> Geoffrey Finlayson, *Citizens, State, and Social Welfare in Britain, 1830-1990* (Oxford, 1990); Geoffrey Finlayson, 'A Moving Frontier: Voluntarism and the State in British Social Welfare, 1911-1949', *Twentieth Century British History*, 1 (1990), pp. 183-206; Jane Lewis, 'Family Provision of Welfare in the Mixed Economy of Care in the late Nineteenth and Twentieth Centuries', *Social History of Medicine*, 8 (1994), pp. 553-56.

<sup>123</sup> For a study of parent organisations and autism, see: Adam Feinstein, *A History of Autism: Conversations with the Pioneers* (Chichester, 2010), pp. 76-115. For an examination of the dynamic between parental advocacy, parent-blaming, and ADHD in the United States and the United Kingdom, see: Marie Reinhold, 'ADHD in Historical and Comparative Perspective: Medical, Educational, and Public Approaches to Childhood Hyperactivity in the US and the UK, 1960-2010', (Vol. 1 of 2, PhD Thesis, University of Manchester, 2012), pp. 310-360.

<sup>124</sup> Frank Prochaska, *The Voluntary Impulse: Philanthropy in Modern Britain* (London, 1988), p. 19.

Sociologist Nick Crossley has examined resistance to psychiatry in post-war Britain, by arguing that a series of Social Movement Organisations (SMOs) emerged. Further, he examines the ways in which these groups became networked, asserting that they became increasingly specialised over time.<sup>125</sup> However, although Crossley mentions the emergence of an 'anti-anti-psychiatry movement', he focuses on the way in which these groups, including the National Schizophrenia Fellowship, positioned themselves against the anti-psychiatry movement rather than their functioning as carer organisations. Further, by focusing on psychiatry, rather than mental health care more broadly, and on anti-anti-psychiatry, rather than carer organisations, Crossley does not explore the interplay between SMOs for mental deficiency and mental illness.<sup>126</sup> This is despite parent organisations for mental deficiency being set up more than twenty years before the first parent organisations for mental illness. By examining the National Schizophrenia Fellowship as an organisation in its own right, rather than simply as an adversary to anti-psychiatry, and also by employing Mencap as a case study, this thesis provides a more in-depth analysis of the role of parent and carer groups.

Historians examining the service-user movement have often overlooked parent and carer groups, and by extension the dynamic, and often tense, relationship between service-user and carer groups. For example, historian Alex Mold has examined the emergence of service-user groups, but overlooks the

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<sup>125</sup> Nick Crossley, *Contesting Psychiatry: Social Movements in Mental Health* (London and New York, 2006), pp. 1-9 and pp. 20-1. For further information on social movements, see Matthew Hilton, James McKay, Nicholas Crowson and Jean-François Mouhot, "'The Big Society': Civic Participation and the State in Modern Britain', *History and Policy* (June 2010); Alex Mold, 'Making the Patient-Consumer in Margaret Thatcher's Britain', *The History Journal*, 54:2 (2011), pp. 509-28.

<sup>126</sup> Crossley, *Contesting*, p. 5.

interplay with these and carer groups.<sup>127</sup> Whilst historian Jonathan Toms has explored the history of parent organisations in relation to the mental hygiene movement, with his research into the relationship between MIND and the National Schizophrenia Fellowship, he has not explored the history of the family carer.<sup>128</sup>

Voluntary action scholars have tended to focus heavily on the relationship between the state and non-governmental organisation (NGO) activity. Indeed, Prochaska has argued that government funding for voluntary organisations in post-war Britain led to a loss of independence among charities.<sup>129</sup> His argument has been criticised because he put too much emphasis on the state, and because of his assumption that the voluntary impulse had ended.<sup>130</sup> However, Alex Mold and Virginia Berridge have helped to reconcile this potential conflict in their study of drug policy NGOs. They argue that the independence of NGOs was not restricted by state funding to the extent suggested by Prochaska, because whilst working *with* the state, they also worked *outside* it. Yet, as state funding increased from the 1980s onwards NGOs had to provide greater value for money and this was what led to greater conformity with governmental policy agendas.<sup>131</sup> In this thesis, I acknowledge that the state contributed to the funds of the voluntary organisations, but suggest that the lobbying activities of these groups are of particular relevance to the story of the emergence of the family carer, with these groups raising the issue of family care-givers before Parliament.

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<sup>127</sup> Mold, 'Patient-Consumer', pp. 509-28.

<sup>128</sup> Jonathan Toms, *Mental Hygiene and Psychiatry in Modern Britain* (Basingstoke, 2013).

<sup>129</sup> Prochaska, *Voluntary Impulse*, pp. 4-5.

<sup>130</sup> Mathew Hilton, James McKay, Nicholas Crowson and Jean François Mouhot, "'The Big Society': Civic Participation and the State in Modern Britain', *History and Policy*, June 2010. <<http://historyandpolicy.org/papers/policy-paper-103.htm>> (17 April 2012), pp. 1-8.

<sup>131</sup> Virginia Berridge and Alex Mold, *Voluntary Action and Illegal Drugs: Health and Society in Britain Since the 1960s* (Basingstoke, 2010).

The study of voluntary action also provides an opportunity to trace the changing nature of welfare and citizenship in post-war Britain.<sup>132</sup> A research group at the University of Birmingham has, over recent years, been compiling a broad history of NGOs (non-governmental organisations) in Britain since 1945. The group, led by Matthew Hilton and Nicholas Crowson has argued that whilst NGOs have existed in one form or another for centuries, there has been 'a persistent growth in the number of socio-political actors' since 1945 and that 'arguably, the period from the 1970s and 1980s onwards has been something of a golden age for voluntarism.'<sup>133</sup> During the post-war years expert citizens drew upon their cultural capital to set up voluntary organisations which catered for a particular group in society and particular interests.<sup>134</sup> Hilton and Crowson have consequently also argued for a longer history of the 'Big Society', in terms of the relationship between NGOs and the welfare state.<sup>135</sup> Regardless, they argue that the 1980s onwards saw a change in the dynamic between the state and voluntarism with Thatcherism and New Labour placing new emphasis on individualism.

### iii. The Post-War Family

Unsurprisingly, historians of the family have been particularly concerned with examining the influence of these demographic, structural, and societal continuities

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<sup>132</sup> Finlayson, *Citizens*.

<sup>133</sup> Matthew Hilton, Nick Crowson, Jean-François Mouhot, and James McKay, *A Historical Guide to NGOs in Britain: Charities, Civil Society, and the Voluntary Sector since 1945* (Basingstoke, 2012), p. 13, p. 23, p. 36.

<sup>134</sup> For cultural capital, see: Pierre Bourdieu, 'The Forms of Capital' in Richardson (ed.), *Handbook of Theory and Research for the Sociology of Education* (Westport, 1986), pp. 234-44. For the expert citizen, see: Matthew Hilton, James McKay, Nicholas Crowson and Jean-François Mouhot, "'The Big Society': Civic Participation and the State in Modern Britain', *History and Policy* (June 2010), p. 7.

<sup>135</sup> Hilton, McKay, Crowson and Mouhot, 'The Big Society', pp. 1-8.

and changes, both for the actuality, and societal norms, of the family.<sup>136</sup> This literature has also asserted that the study of the family needs to be approached in new ways, with sociologists Leonore Davidoff, Megan Doolittle, Janet Fink and Katherine Holden suggesting that 'treating the family as a closed, single entity has made it difficult to look at internal relationships in terms of gender, generation and other inequalities'.<sup>137</sup> This thesis argues that new interest in, and understandings of, the family during the post-war years, based around notions including pathology, nurture, emotion, and responsibility contributed to changing expectations of family care-givers and the emergence, and subsequent negotiation, of the category of the carer.

Historian Pat Thane has challenged the fixed meaning of the early-post war 'normal' family stressing that 'stable, long-lasting marriage' was in fact an exceptional characteristic of this period.<sup>138</sup> Thane has argued, 'the 1930s to 1950s was . . . the only age, of the near universal, stable, long-lasting marriage, often considered the normality from which we have since departed.'<sup>139</sup> Thane's work is part of a recent move by scholars to destabilise traditional histories of the family, where "'the family" is often implicitly taken to be an essential and natural entity'.

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<sup>136</sup> April Gallwey, 'Lone Motherhood in England, 1945-1990: Economy, Agency, and Identity (PhD Thesis, University of Warwick, 2011); Katherine Holden, 'Family, Caring and Unpaid Work', in Ina Zweiniger-Bargielowska (ed.), *Women in Twentieth-Century Britain* (Harlow, 2001); Kathleen Kiernan, Hilary Land and Jane Lewis, *Lone Motherhood in Twentieth-Century Britain: From Footnote to Front Page* (Oxford, 1998); Pat Thane, 'Family Life and "Normality" in Postwar British Culture', in Richard Bessel and Dirk Schumann (eds), *Life After Death: Approaches to a Cultural and Social History of Europe during the 1940s and 1950s* (2003); Thane, *Old Age*.

<sup>137</sup> Leonore Davidoff, Megan Doolittle, Janet Fink and Katherine Holden (eds), *The Family Story: Blood, Contract and Intimacy, 1830-1960* (Harlow, 1999).

<sup>138</sup> Thane, 'Family Life', p. 198.

<sup>139</sup> Thane, 'Family Life', p. 198. Note that a similar argument in: Pat Thane, *Happy Families? History and Family Policy* (British Academy, 2010) was critiqued in Rebecca Probert, 'Happy Families? History and Family Policy' *Law Quarterly*, 23:2 (2011). In this article, Probert deemed Thane's assertions unreliable, because they did not match up to quantitative data from the period. However, these challenges have since been readdressed in a revised version of Thane's booklet.



Instead, these scholars are weary of over-generalisations and assumptions about 'the family', critiquing, for example, the notion of a golden age for the nuclear family.<sup>140</sup> However, concerns over the changing nature of family structure in Britain, whether real or perceived, were a common and prevalent theme, especially during the 1970s, amongst politicians, social scientific researchers, and medical professionals. Although often associated with the New Right, concerns were also expressed by those on the left-wing of politics.<sup>141</sup>

Another critique of the notion of the golden age of the family has been provided by historical study of 'the problem family.' John Welshman has persuasively argued that the notion of the 'problem family' has a long historical trajectory. This emerges clearly in his examination of thinking about the relationship between families and transmitted deprivation between early twentieth-century eugenics and New Labour.<sup>142</sup> Historian George Behlmer has pushed this concern about the family back to the 1850s. However, he indicates that the main concern was 'specific problems - domestic violence, juvenile criminality, and the fate of illegitimate children', implying that it was not until the post-war years that political concern focused on the family unit as a whole.<sup>143</sup> Overall, this work suggests that concern about the problem family, rather than of concerns

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<sup>140</sup> Davidoff, Doolittle, Fink, and Holden (eds), *The Family*, pp. 4-7.

<sup>141</sup> John Welshman, 'Ideology, Social Science, and Public Policy: The Debate over Transmitted Deprivation', *Twentieth Century British History*, 16:3 (2005), p. 328.

<sup>142</sup> John Welshman, *From Transmitted Deprivation to Social Exclusion: Policy, Poverty, and Parenting* (Bristol, 2012); John Welshman, *Underclass: A History of the Excluded since 1880* (London, 2013); John Welshman, 'In Search of the "Problem Family": Public Health and Social Work in England and Wales 1940-70', *The Society for the Social History of Medicine*, 9 (1996), pp. 448-65; Welshman, 'Ideology', pp. 306-41.

<sup>143</sup> George K. Behlmer, *Friends of the Family: The English Home and Its Guardians, 1850-1940* (Stanford, 1998), p. 2.

about behaviour within the family, became more acute in the period of the 1940s-1970s.

Historians have related concerns over problem families with concurrent fears over the loss of traditional family groups and their values.<sup>144</sup> Behlmer has argued that moral panics over the decline of family values were particularly prominent in after the Second World War, and particularly in relation to the permissive society, but that the family has '*never* been able to meet the expectations placed upon it'.<sup>145</sup> Family values, according to Behlmer, were being called into question in the nineteenth and twentieth centuries, and continued to be questioned under both Thatcherism and New Labour.<sup>146</sup>

During the post-war years women were often assumed to be natural care-givers, and it was often assumed that all family carers were women. Despite the emergence of the welfare state, a mixed-economy of voluntary welfare and care provided by relatives endured.<sup>147</sup> Indeed, the assumption of women as care-givers was one of the bases of the welfare state which followed a male breadwinner and female homemaker model, but which was out of line with changes in women's labour patterns.<sup>148</sup> Much of this scholarship critiquing women as natural care-givers has been conducted by feminist scholars and is strongly based on contemporary

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<sup>144</sup> John Welshman, *Underclass: A History of the Excluded, 1880-2000* (London, 2006), p. 67, p. 81; This concern over the loss of traditional family values was also evident in contemporary social surveys, including: Michael Young and Peter Willmott, *Family and Kinship in East London* (3<sup>rd</sup> edn, London, 2007), p. 31, p. 76, p. 86, p. 116. p. 124, pp. 139-40, p. 147.

<sup>145</sup> Behlmer, *Family*, p. 318. See also: Roy Porter, 'Anti-Psychiatry and the Family: Taking the Long View', in Gijswijt-Hofstra and Porter, *Cultures of Psychiatry*, p. 257; Charles Anthony Butterworth and David Skidmore, *Caring for the Mentally Ill in the Community* (London, 1981), pp. 38-39.

<sup>146</sup> Behlmer, *Family*, p. 323-24.

<sup>147</sup> Finlayson, *Citizens*; Finlayson, 'A Moving Frontier', pp. 183-206; Lewis, 'Family Provision', pp. 553-56.

<sup>148</sup> Angela Davis, *Modern Motherhood: Women and Family in England, c. 1945-2000* (Manchester, 2012), pp. 177-206.

feminist theory.<sup>149</sup> Notably, sociologist Janet Finch argued that the state expected women to become care-givers, especially from the 1970s onwards.<sup>150</sup> Historian Katherine Holden has also explored the relationship between families, caring, and the state, with specific reference to old age care. Significantly, however, Holden did not address the phenomenon of women and men caring for relatives with mentally illnesses and learning disabilities within their family. Holden argued in terms of single women caring for elderly relatives, 'the fact that many women saw [caring] tasks as obligations to their family enabled the state to make considerable savings in providing for the needs of its dependent members.'<sup>151</sup> However, Holden suggested that this natural role was destabilised in the 1980s and 1990s as more women entered into full-time work, a shift which clashed with women's ability to become care-givers.<sup>152</sup> This tension was exacerbated by concerns, referred to earlier in this introduction, relating to an ageing population and changing family structures. This tension led to debates about who should, could, or would provide care. It also led to calls for reform to the welfare state, given that it was based on a notion of the family which did not exist across the board by the 1970s.<sup>153</sup>

Whilst this thesis is concerned with the history of family carers, the focus is often on parents, and particularly mothers. Behlmer, Angela Davis, and Mathew Thomson have examined the influence of advice literature and child guidance

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<sup>149</sup> Jane Lewis, 'The Decline of the Male Breadwinner Model: Implications for Work and Care', *Social Politics*, 8:2 (2001), pp. 152-70.

<sup>150</sup> Janet Finch, *Family Obligation and Social Change* (Cambridge, 1989); Janet Finch and Jennifer Mason, *Negotiating Family Responsibilities* (London, 1993).

<sup>151</sup> Holden, 'Family', p. 137.

<sup>152</sup> *Ibid.*, p. 134-48.

<sup>153</sup> Karen Rowlingson, "'From Cradle to Grave': Social Security over the Life Cycle", in Jane Millar (ed.), *Understanding Social Security: Issues for Policy and Practice* (Bristol, 2003), p. 12; Lewis, 'Breadwinner', pp. 153-55.

experts on parenting styles in the inter-war years and the post-war period.<sup>154</sup> As Davis has argued based on oral history interviews, women were exposed to a variety of childcare manuals but they 'recalled childcare experts in an ambivalent manner and held contradictory feelings about their advice.'<sup>155</sup> However, Davis goes on to conclude that mothers were made to feel responsible for the physical and psychological well-being of their children and that experts used new rationales to reinforce women's place in the home after the Second World War.<sup>156</sup> Indeed, 'very few [women] took a job when their children were under five.'<sup>157</sup> In other words, expert advice helped to enforce a certain model of the family and maternal responsibility.

After the Second World War, child psychologists tended to stress the important role of parents, and in particular, mothers in the development of their children. Historians, including Davis and Thomson, have examined the influence of child guidance specialists, including John Bowlby and Anna Freud.<sup>158</sup> Harry Hendrick has also explained how the notion of children as future investments of the state in the twentieth century, was closely associated with correct and adequate parenting.<sup>159</sup>

Anne Borsay and Pamela Dale have examined various aspects of the experiences of the families, and in particular the parents, of disabled children, particularly in terms of the development of these children. For instance, they have

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<sup>154</sup> Behlmer, *Family*, pp. 130-31; Davis, *Motherhood*, pp.112-36; Thomson, *Lost Freedom*, pp. 79-105.

<sup>155</sup> Davis, *Motherhood*, pp.136.

<sup>156</sup> *Ibid.*, pp. 209-10.

<sup>157</sup> *Ibid.*, p. 170.

<sup>158</sup> Davis, *Motherhood*, pp. 112-36; Thomson, *Lost Freedom*, pp. 79-93.

<sup>159</sup> Harry Hendrick, *Child Welfare: Historical Dimensions, Contemporary Debate* (Bristol, 2003), pp. 13-14. See also: Anne Borsay, 'From Representation to Experience: Disability in the British Advice Literature for Parents, 1890-1980', in Borsay and Dale, *Disabled Children*, pp. 91-101.

examined the relationships between parents and professionals. Borsay and Dale assert that childhood disability is different from adult disability, particularly because experts attempted to intervene, via parents, in the upbringing of disabled children to try and ensure they could become independent adults.<sup>160</sup> In this thesis, I argue that parents of mentally handicapped children were trained to assist their children and this was often to work towards the child's independence in adulthood.

In summary, historians have struggled to pin down, and discretely define the concept of the post-war 'family', not least because the concept was itself in flux during the decades following the Second World War. Indeed, the family meant different things to different interested parties during the period, from the problem family, to the nuclear family, and the immigrant family to the pathological or therapeutic family.<sup>161</sup> Broadly speaking, whilst the family had often been put forward as the ideal place for children to grow up, in the care of their mothers, by the 1970s the family as a site of care and child development was viewed with anxiety and a lack of confidence by both right- and left-wing politicians.<sup>162</sup> The carer was a site of this paradox, with concerns over the pathological nature of families, but also of the need for families to become care-givers for relatives with mental illnesses and learning disabilities.

#### **iv. Sociology, Psychology, and the Psychosocial**

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<sup>160</sup> Borsay and Dale, *Disabled Children*.

<sup>161</sup> For an introductory overview of changing notions of the family in post-war Britain, see: Michael Peplar, *Family Matters: A History of Ideas about the Family since 1945* (London and New York, 2002), pp. 1-16.

<sup>162</sup> Thomson, *Lost Freedom*, pp. 79-105.

The disciplines of social science and the psychosocial, which grew in popularity during or shortly after the Second World War, shaped and helped to create new social phenomena, including the family carer. Research by those working in these disciplines is a focus of this thesis. Although becoming interested in the issue of family carers for mental illness and mental handicap for different reasons, these researchers, who often employed inter-disciplinary methodologies, played an important role in the emergence of the category of the carer. Researchers entered the family home and examined, identified, and publicised issues including emotional relationships within the family, the well-being of relatives, and the number of family care-givers.

During the post-war years, the question of how to define mental illness and mental handicap, and the impact of family care-givers on those with mental illnesses and learning disabilities, came to the attention of an expanding field of social science. With the closure of long-stay institutions, the failure of psychiatry to provide comprehensive answers about causes and cures, and the rise in popularity of sociology and psychology, mental illness and mental handicap became a social scientific, as well as a psychiatric, issue.

Sociology became more influential and respected after the Second World War and sociologist Mike Savage has demonstrated how a particular instrument of social scientific study, the social survey, allowed social scientists to create and shape new phenomena at this time. Social researchers examined familial and societal change and continuity firstly via community-based studies in the 1950s, typified by the Institute of Community Studies, and then via national, longitudinal

studies by the 1980s, notably the General Household Survey.<sup>163</sup> Historian Angela Davis has suggested that the interest of social scientists and sociologists in research based on the family had waned by the 1970s.<sup>164</sup> Rather than fading completely, however, I argue that, research into the family became subsumed within state-sponsored longitudinal surveys, such as the General Household Survey, or focused on more specific issues, such as informal care. This change reflected concern from both the left- and right-wing of politics about the family from the 1970s onwards, with the state becoming more anxious to know more about British families. Savage argues that social scientists had a considerable impact in the post-war period. Social scientists, he argues, investigated social and community change, mapped the modern nation for the state, and often shared a reciprocal relationship with the social policy makers.<sup>165</sup>

An aspect which Savage does not fully consider, but which was significant in the emergence of the family carer, was the influence of psychosocial research. Historians Rhodri Hayward and Mathew Thomson have argued that psychology became popularised, and popular, during the twentieth century, with psychology influencing health care, identity, and indeed social scientific research.<sup>166</sup> The psychosocial was a field of expertise and enquiry which was particularly a product of the Second World War and the immediate post-war years.<sup>167</sup> The psychosocial combined approaches, methodologies, and research subjects from sociology and

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<sup>163</sup> Savage, *Identities*. See also: David Armstrong, 'Medical Sociology', in W.F. Bynum and Roy Porter (eds), *Companion Encyclopaedia of the History of Medicine* (London, 1993), p. 1643. See also: Nikolas Rose, 'Psychology as a Social Science', *Subjectivity*, 25:1 (2008), p. 452-53; Thomson, *Mental Deficiency*, p. 241-44.

<sup>164</sup> Davis, *Modern Motherhood*, p. 15.

<sup>165</sup> Savage, *Identities*. See also: Armstrong, 'Medical Sociology', p. 1643. See also: Rose, 'Psychology', p. 452-53; Thomson, *Mental Deficiency*, p. 241-44.

<sup>166</sup> Hayward, *Transformation*; Thomson, *Psychological Subjects*.

<sup>167</sup> Hayward, *Transformation*, pp.77-81.

psychology, and became an area of interest across-disciplinary boundaries, for sociologists, anthropologists, psychiatrists, psychologists, and social workers, encouraging researchers to consider environmental factors in their understandings of disease and illness.<sup>168</sup> During the Second World War the discipline of psychology expanded beyond the study and measurement of mental ability, normality, and social norms, to 'a psychology of social relations and by the use of psychology as a diagnostic and therapeutic tool'.<sup>169</sup> This interest in psychology was also to influence the field of psychiatry and encouraged psychiatrists, and others, to re-examine social-economic factors and the environment of the family in their understandings of mental illnesses. 'Large-scale surveys into the relationship between environment and mental health attempted to recover increasingly detailed information regarding the lives of their respondents', including 'family interactions'.<sup>170</sup> In the case of the family carer, those researching the psychosocial, or social psychiatry, became interested in the family, and care-giving, as a by-product of their interest in mental illness and mental handicap.

The turn to the psychosocial in summary saw experts employing new 'tools, methods, and concepts' to map new spaces and new experiences, which in turn created new psychosocial categories.<sup>171</sup> This thesis provides a case study of such development as it traces how researchers at the Medical Research Council's Social

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<sup>168</sup> Rhodri Hayward, 'The Invention of the Psychosocial: An Introduction', *History of the Human Sciences*, 25:3 (2012), p.3; Hayward, *Transformation*, pp. 77.

<sup>169</sup> Mathew Thomson, 'The Psychological Body', in Roger Cooter & John Pickstone (eds.), *Medicine in the Twentieth Century* (Abingdon, 2000), pp. 295-96. See also, Thomson, *Psychological Subjects*, pp. 209-294.

<sup>170</sup> Hayward, 'Sadness', pp. 332-33.

<sup>171</sup> Hayward, 'The Invention', pp. 7-8. See also: Joanna Bourke, *Dismembering the Male: Men's Bodies, Britain, and the Great War* (London, 1996); Joanna Bourke, 'How do Physical Bodies Affect Social Change?', in Harriet Swain (ed.), *Big Questions in History* (London, 2005), pp. 235-41; Thomson, *Psychological Subjects*; Mathew Thomson, 'Psychological Subjects: Response', *History of the Human Sciences*, 20:3 (2007), pp. 141-47.



Psychiatry Unit employed a broad range of techniques and theories in beginning to uncover the role of family relations and care in the framing of mental health problems. As psychosocial studies academic David W. Jones has argued for a dynamic relationship between psychiatry and the family, with psychiatry's conceptions of the family having an impact on the families themselves, and in which families are also revealed as 'active agents in shaping the practices and boundaries that surround mental illness.'<sup>172</sup>

Using the case study of hyperactivity in the United States context, historian Matthew Smith has demonstrated the relationship between social psychiatry and a focus, not purely on the mentally ill individual, but rather on the collective, social, prevention of mental illness, or the preservation of mental health.<sup>173</sup> I argue that deinstitutionalisation, and the movement of patients to the community, meant that psychosocial experts became interested in the impact of the community, and more discretely of the family, on the preservation of mental well-being. In addition to researchers from the Social Psychiatry Unit, R.D. Laing and David Cooper, who were associated with the anti-psychiatry movement, were also interested in the social relationships of families. However, rather than using this research to support the well-being of family members, as social psychiatrists tended to do, it formed the basis of their critique of the family, as a repressive institution.<sup>174</sup>

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<sup>172</sup> Jones, 'Madness', pp. 247-72. Jones also utilised interviews to examine feelings of shame, loss, and ambivalence amongst families with a seriously mentally ill relative: David W. Jones, 'Shame and Loss: Narrative and Identity in Families with a Member Suffering from Mental Illness', *The International Journal of Critical Psychology*, 10 (2003), pp. 69-93; David W. Jones, 'Families and Serious Mental Illness: Working with Loss and Ambivalence', *British Journal of Social Work*, 34 (2004), pp. 961-79.

<sup>173</sup> Matthew Smith, 'Psychiatry Limited: Hyperactivity and the Evolution of American Psychiatry, 1957-1980', *Social History of Medicine*, 21:3 (2008), pp. 541-59.

<sup>174</sup> Deborah Cohen, *Family Secrets: The Things We Tried to Hide* (London, 2014), pp.212-40; Porter, 'Anti-Psychiatry', pp. 257-75.

Among other achievements, Hayward's work has been particularly insightful when it comes to the emergence of psychosocial concern about stress.<sup>175</sup> Such work provides a model for how we might study changing conceptualisations of emotional relationships within the family. In doing so, we would also be following the call and example of sociologists for historical study of relationships *within* the family.<sup>176</sup> The potential for such work is also exemplified in social historian Claire Langhamer's recent account of the interplay between marriage, family, and emotional love, which joined the family as a key characteristic of English society after the Second World War.<sup>177</sup> Another way to examine the emotional relationships within the family is to examine the domestic space of the family home, which like the family itself, has been conceptualised as a site and environment of both therapy and pathology. Mark Jackson's volume, *Health and the Modern Home* explores the family home as an emotional environment.<sup>178</sup> Contributions to the collection examine housewife neurosis in inter-war and post-war Britain and psychiatric social workers entering the family home.<sup>179</sup> In this thesis, I demonstrate that film and television were particularly adept at bringing the work of those interested in the psychosocial to life, as the screen provided an ideal medium for family interactions, relationships, and dialogue.

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<sup>175</sup> Hayward, 'The Invention', pp. 3-12. For a history of stress, see: Mark Jackson, *The Age of Stress: Science and the Search for Stability* (Oxford, 2013).

<sup>176</sup> Davidoff, Doolittle, Fink and Holden, *The Family Story*.

<sup>177</sup> Clare Langhamer, *The English In Love: The Intimate Story of an Emotional Revolution* (Oxford, 2013).

<sup>178</sup> Mark Jackson, "'Home Sweet Home': Historical Perspectives on Health and the Home", in Mark Jackson (ed.), *Health and the Modern Home* (New York, 2007), p. 2,

<sup>179</sup> Ali Haggart, 'Housewives, Neurosis, and the Domestic Environment in Britain, 1945-70', in Jackson, *Health and the Modern Home*, pp. 84-110; Rhodri Hayward, 'Desperate Housewives and Model Amoebae: The Invention of Suburban Neurosis in Inter-War Britain', in Jackson, *Health and the Modern Home*, pp. 42-62; John Stewart, "'I Thought You Would Want to Come and See His Home': Child Guidance and Psychiatric Social Work in Inter-War Britain", in Jackson, *Health and the Modern Home*, pp. 111-127; John Welshman, 'Social Science, Housing, and the Debate Over Transmitted Deprivation', in Jackson, *Health and the Modern Home*, pp. 266-84.

## **Source-Base and Thesis Outline**

### **i. Source-Base**

Throughout this thesis I explore the key events, episodes, and issues which are fundamental to the story of the acknowledgement and negotiation of the category of the carer. As this thesis is primarily concerned with a history of ideas and debates about and surrounding the issue of familial carers, I have opted to adopt a broad source base which has enabled me to access a range of voices and interactions between these interested parties. Rather than being compartmentalised into one particular field of history, this thesis draws upon the methodologies of the histories of social policy, social research, the media, voluntary action, the political and social history of post-war England and Wales, and mental health care. In many respects, it is best categorised as a history of the politics of ideas.<sup>180</sup>

I adopt a qualitative approach which pays particular attention to debates and discussion regarding familial care-giving and family carers in the mental health context. Historians of nineteenth-century psychiatry have tended to use the, sometimes rich, resource of asylum archives, helpfully falling outside the one-hundred year rule. These historians have managed to garner an insight into the relationship between relatives, psychiatrists, the patient, and the asylum by reading

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<sup>180</sup> An approach which draws upon methodologies from various different fields and themes within history has been advocated by scholars at the University of Birmingham: Centre for Modern British Studies, 'Modern British Studies'.

across the grain in case histories, using letters from patients, psychiatrists, and relatives as a source, and employing any other source in the asylum archive, or in the writings of the particular psychiatrist to gain an insight.<sup>181</sup> Indeed, I adopted this approach in my undergraduate dissertation on the role of relatives in the admissions to, and discharges from, an asylum in Bedfordshire, the Three Counties Asylum, in the late-nineteenth century. It is technically possible to view archival material outside of the one-hundred year rule, but given the complexities of this, and also the often tangential view of relatives offered by asylum records I decided to adopt another approach. Drawing upon examples of histories of care outside of the asylum or mental deficiency colony written by the authors included in the volume *Outside the Walls of the Asylum* and by Mathew Thomson in *The Problem of Mental Deficiency*, I decided to centre my analysis on the way in which a range of actors wrote about care within the community and the family home. As such I have used a wide range of source material to allow me to begin examining the broad range of actors who became interested in family care-giving in the post-war years. Whilst the thesis is broadly structured around these source bases, a source used heavily in one chapter was often also relevant to another, not least because some of the key figures mentioned within this thesis were influential across different spheres.

The social policy source material was largely derived from Hansard, social policy documents, including white papers, green papers, committee reports, and Acts of Parliament, archival deposits for particular politicians, books published by

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<sup>181</sup> Jonathan Andrews, 'Case Notes, Case Histories and the Patients' Experience of Insanity at Gartnavel Royal Asylum Glasgow in the Nineteenth Century', *Social History of Medicine*, 11 (1998), pp. 251-81.

politicians, social commentaries, and newspaper articles. To write the social scientific research section of this thesis I drew upon published survey results, survey and questionnaire designs and schedules, and journal articles written by social scientists across a range of sub-disciplines. Media sources included documentary-dramas, films, novels, and film studies literature. The parent and carer organisation material was often disparate, with Mencap having a private archive, the National Schizophrenia Fellowship's having a rich deposit in the Wellcome Library collection, and published material and journals being more widely available. One of the reasons I chose to focus on Mencap and the National Schizophrenia Fellowship was the accessibility of documents and sources relating to these groups. Some relevant organisations do not have an archive at all or have private archives which are difficult to access, sometimes simply because they do not have the required facilities. The Database for Non-Governmental Organisations (DANGO) website is a particularly helpful resource to historians of the voluntary sector, and the campaign for voluntary archives, supported by the Voluntary Action History Society is working for material like this to be made more accessible. Unfortunately the archival material for the National Association of Mental Health, or MIND, is currently unavailable for access as it is awaiting cataloguing in the Wellcome library. Given the time period of this thesis it was often the case that secondary source material could also be utilised as a primary source, i.e. books published on community care in the 1960s and 1970s.

An alternative route to study the history of the emergence of the family carer would be an analysis of memoirs and oral history interviews conducted with family carers themselves. Such an approach, however, would shift the focus to the

history of the everyday experience of family carers rather than the prime concern of this thesis which is the politics of family care. Nevertheless, this thesis does include some insight into the day-to-day experiences of relatives, which has been sourced, for instance, from parent and carer organisation newsletters.

## **ii. Thesis Outline**

Using parliamentary papers as its main source-base, Chapter One will provide an overview of social policy discussions and debates, as well as legislative changes relevant to the carer for mental illness and learning disability. I examine how the family carer became and remained an object of the social policy agenda in England and Wales during the latter half of the twentieth century. Engaging with contemporary debates from interest groups, including second-wave feminists and carer organisations, I examine debates about who should, would, or could provide care: the state or the family.

Chapter Two utilises social surveys and analysis to consider the various ways in which the family carer became the subject of social scientific research after the Second World War at a time when social scientific surveys were becoming increasingly respected and utilised as tools by both academics and the state. Examining local and national, sociological and demographic research, the chapter argues that social researchers became interested in the carer for a number of reasons, not least because family carers were at the intersection of a number of research interests of the time, including community care, mental illnesses, child development, the family, and social care. In the early post-war years the

phenomenon of care for those with mental illnesses and learning disabilities within the home became more visible to social researchers as they entered the family home, and subsequently as the government attempted to map a national picture of familial carers via the General Household Survey.

Using a media source-base, including television, film, and press material, Chapter Three focuses on television and film representations of families caring for relatives with mental illness or learning disabilities. During the post-war years, spurred on by institutional closures, a range of professionals, including child psychologists, social psychiatrists, and anti-psychiatrists attempted to better understand the role of social environment, family, and social relationships in the causes and treatments for mental illnesses and the training for children with learning disabilities. As dialogue and dynamic relationships were key to the resulting therapeutic methods, such as family therapy, documentaries and documentary dramas were the ideal media through which to introduce the public to the complications and contradictions evident in the lives of family carers.

Carer organisation case studies are examined in Chapters Four and Five, which focus on material produced and published by Mencap (previously the National Association for the Parents of Backwards Children and the National Society for Mentally Handicapped Children) and the NSF (later known as Rethink: Mental Illness), respectively. These chapters examine why Mencap was founded twenty years before the NSF and consider whether this reflects the fact that there were earlier moves towards community and familial care for mental handicap than for mental illness. Chapters Four and Five also cast light on the history of rights discourse, and collective action, on the one hand (through the role of these

organisations as pressure groups), and of emotion, class, and the family on the other (because study of these groups also casts light on the relationship between the social status of the activists and the politics of care).

Chapter Six focuses on the issues, complexities, and strengths of considering the history of the family carer for mental illness alongside the history of the family carer for learning disability. This chapter functions as the first stage of the conclusion of this thesis and has been deemed to warrant separate analysis as the distinction and relationship between mental illness and learning disability is an important thread which recurs throughout the thesis. Mental health care throughout the post-war period included the mentally ill and the mentally handicapped within its remit, even once mental handicap was re-allocated to the Department of Education and Science in 1968. Historian John Welshman made a start in examining the interrelated histories of mental illness and learning disability, but did so as a historian of social policy rather than as a historian of mental health care or social history, which are the broad approaches of this thesis. A study of the complex relationship between the histories of mental illness and learning disability affords historians the opportunity to ask new questions and develop new lines of inquiry, and I reflect on the implications of this analysis in this final chapter.

In the conclusion of this thesis I include an epilogue which follows the story of the place of the family carer in mental health care, albeit in brief, from c. 2000 to 2011. The purpose of this section is to demonstrate that the family carer continued to emerge following the trajectory set out by the 1999 National Strategy for Carers in the respect that carers were considered to have a vital role, were thought of in their own right rather in relation to their dependents, and did not need to fulfil



thirty-five hours of caring a week to be considered family carers. I then summarise and discuss the main findings of the thesis to argue that the years 1946-1999 were significant in the history of the role, emergence, and place, of the family carer in English and Welsh mental health care. Finally, I reflect upon ways in which the remit of this thesis could be helpfully extended and expanded in future scholarship.

# 1.

## The Family Carer as an Object of Social Policy, c. 1954-1999

In this chapter I argue that from the 1970s and particularly in the 1980s and 1990s the carer, including those caring for people with mental illnesses and mental handicaps, came to be on the social policy agenda. The focus is on the debates and discussions amongst social policy makers and other interested parties on the issue of who should, could, or would provide care in the era of the welfare state: the state or the family. Whilst family carers were only implicitly mentioned in the 1954-57 Report of the Royal Commission on the Law Relating to Mental Illness, by the late 1980s they were noted as the main providers of community care in the White paper *Caring for People* (1989).<sup>1</sup> This acknowledgement was closely followed by the 1995 Carers (Recognition and Services) Act and the 1999 National Strategy for Carers.<sup>2</sup> Despite there being a long history of familial care for relatives with mental illnesses and learning disabilities in the home, examined in particular by historians

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<sup>1</sup> *Report of the Royal Commission on the Law Relating to Mental Illness and Mental Deficiency, 1954-1957* (London, 1957), p. 30, p. 211; Department of Health and Department of Social Security, *Caring for People: Community Care in the Next Decade and Beyond* (London, 1988), Cm. 849, p. 9.

<sup>2</sup> *Carers (Recognition and Services) Act* (London, 1995); Department of Health, *Caring about Carers: A National Strategy for Carers* (London, 1999).

of the nineteenth century as outlined in the thesis introduction, it was not until the late 1950s that community care became an explicit government policy. The 1959 Mental Health Act and Enoch Powell's 1961 Water Tower Speech have long been considered a watershed moment in the history of mental health care in the United Kingdom.<sup>3</sup> In fact, care in the community has a much longer history.<sup>4</sup> Nevertheless, the decision by the Conservative government to move towards the closure of long-stay institutions for mental illness and mental handicap was significant in the formalisation of a policy of community care.<sup>5</sup> What is less well recognised, and what this thesis sets out to emphasise, is that this shift was also crucial in the emergence and subsequent negotiation of the category of the carer.

The term 'community care' was critiqued throughout the post-war years as having no clear meaning. Aside from favouring a move away from care in residential institutional settings, community care had different meanings to different people, not least because of a lack of consensus over what constituted 'community' and 'care'.<sup>6</sup> This ambiguity in definition left room for debate and contestation, which was often the product of uncertainty of what community care policies would look

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<sup>3</sup> Kathleen Jones, *A History of Mental Health Services* (London, 1972); Kathleen Jones, *Mental Health and Social Policy, 1845-1959* (London, 1960).

<sup>4</sup> Peter Barham, *Closing the Asylum: The Mental Patient in Modern Society* (London, 1992), p. 11; Peregrine Horden, 'Household Care and Informal Networks: Comparisons and Continuities from Antiquity to the Present', in Peregrine Horden and Richard Smith (eds), *The Locus of Care: Families, Communities, Institutions, and the Provision of Welfare Since Antiquity* (London, 1998), p. 26; Mathew Thomson, *The Problem of Mental Deficiency: Eugenics, Democracy and Social Policy in Britain c. 1870-1959* (Oxford, 1998), p. 294; Mathew Thomson, 'Sterilization, Segregation and Community Care: Ideology and Solutions to the Problem of Mental Deficiency in Inter-War London', *History of Psychiatry*, 3 (1992), p. 487; John Welshman, 'Rhetoric and Reality: Community Care in England and Wales, 1948-74', in Peter Bartlett and David Wright (eds), *Outside the Walls of the Asylum: The History of Community Care, 1750-2000* (London and New Brunswick, 1999), p. 207.

<sup>5</sup> Hugh Freeman, 'The General Hospital and Mental Health Care: A British Perspective', *The Milbank Quarterly*, 73:4 (1995), p. 657; Roy Porter, 'Two Cheers for Psychiatry!' in Hugh Freeman and German Berrios (eds), *150 Years of Psychiatry: The Aftermath* (London, 1996), p. 401.

<sup>6</sup> Peregrine Horden, 'Household Care and Informal Networks: Comparisons and Continuities from Antiquity to the Present', in Horden and Smith, *The Locus of Care*, pp. 35-36; David Skidmore, *The Ideology of Community Care* (London, 1994), p. 1.

like in reality. For example, carer organisations were concerned over whether community care would mean state provided care *in* the community or care *by* relatives. Concurrently, various parties became interested in the issue of carers for mental illness and disability because of broader concerns related to community care. For example, feminists were concerned that community care would mean care by female relatives. Social campaigners, including Fabians, questioned whether the state would take responsibility for caring. Meanwhile, politicians became interested in the debate because of concerns over issues including the ageing population and the closure of mental hospitals within their constituencies.

Historical study of the informal or family carer in social policy can provide insight not only into the relationship between caring and legislation, but also the relationship between the state, parent and carer groups, mental health care professionals, social scientists, and the media. Significantly, the rhetoric of community care began to dominate the mental health care policy agenda at the same time as social movements, including second-wave feminism and carer groups were established and became interested in the role of the family in care. This coincided with a broader shift towards consideration of relatives as carers in social policy debates centred on the care of the elderly and women's work. Tracking the emergence of the carer in social policy discourse and its related documentation, including white papers and Acts of Parliament, allows historians to access debates amongst those trying to influence social policy decisions and ensure that the carer remained on the social policy agenda. As social work academic Ray Jones has commented in the case of children's policy between 1948 and 2008, legislative change is driven by a range of factors: 'It is usually some combination of committed

people, a concern about the poor quality of current provisions or conflicts within legislation, changing social values and contemporary context, and, increasingly, the impact of research and information.<sup>7</sup>

This chapter considers four of the key social policy landmarks in the emergence and negotiation of the category of the carer. These case studies allow me to examine a series of themes which are key not only to the emergence of the carer and the subsequent negotiation of this category, but also to the social policy landscape of post-war British politics. Given that this thesis is particularly concerned with the history of mental health care, the focus will be on mental health legislation. I demonstrate that that this legislation often encompassed mental handicap as well as mental illness. However, I also show that legislation which affected family carers increasingly had a remit broader than just mental health care, especially towards the end of the twentieth century.

Firstly, the *Better Services for the Mentally Handicapped* (1971) and *Mentally Ill* (1975) are put forward as one of the initial moments that family caregivers came to be on the social policy agenda.<sup>8</sup> I examine the role of left-wing social reformers in this emergence and begin to critically reanalyse the history of community care initiatives.<sup>9</sup> Secondly, an examination of the Invalid Care Allowance (ICA, 1976) allows for a study of concerns over the legal assumption that women were natural carers, raised most keenly by second-wave feminists and subsequently analysed by, predominantly female, social policy research academics. Thirdly, a

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<sup>7</sup> Ray Jones, 'Children Acts 1948-2008: the Drivers of Legislative Change in England over 60 years', *Journal of Children's Services*, 4:4 (2009), p. 49.

<sup>8</sup> Department of Health and Social Security, *Better Services for the Mentally Handicapped* (London, 1971); DHSS, *Better Services for the Mentally Ill* (London, 1975).

<sup>9</sup> Note that the *Better Services* white papers did not refer to caring relatives explicitly as 'carers' as these documents were written before the term came into use.

series of reports, debates, committees, and white papers which culminated in the green paper *Community Care: Agenda for Action* (1988) and the National Health Service and Community Care Act (1990) provide access to debates amongst contemporaries, and predominantly sociologists and those involved with the carer lobby, on topics including what a community was, what community care should look like, and who should pay for it.<sup>10</sup> In particular, I examine the interaction between policy makers and the National Schizophrenia Fellowship (NSF). Schizophrenia became a specific issue of debate during the 1980s not least because of its aetiology as a disorder which was incurable and both chronic and acute in nature, which meant that neither long-stay institutions nor pre-existent community-based service provision were considered appropriate loci of care.<sup>11</sup> Finally, I examine the figure of the carer in light of contemporary concerns regarding rights, social entitlement, and concerns over well-being, using the case studies of the Carers (Recognition and Services) Act (1995) and *Caring about Carers: A National Strategy for Carers* (1999).<sup>12</sup>

I argue that central to debates over the place of the carer in post-war mental health care and community care was the issue of who should, could, or would provide care. These debates were facilitated by a lack of consensus over both the vision of what community care could look like and what it would be like in reality. In post-war Britain citizens felt an entitlement to social welfare, and this,

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<sup>10</sup> DHSS, *Community Care: Agenda for Action. A Report to the Secretary of State for Social Services* (London, 1988); DH, *The National Health Service and Community Care Act* (London, 1990).

Note that the *Community Care: Agenda for Action* green paper is commonly referred to as the Griffiths Report.

<sup>11</sup> J. Hoeing, 'Schizophrenia: Clinical Section', in G.E. Berrios and Roy Porter (eds), *A Clinical History of Psychiatry: The Origin and History of Psychiatric Disorders* (London, 1995), p. 337.

<sup>12</sup> *Carers (Recognition and Services) Act*; DH, *Caring about Carers*.

combined with the day to day experience of care-giving, meant that some relatives and supporters of carers' interests resisted the notion of care *by* the community.<sup>13</sup> However, paradoxically, at the same time they wanted to be perceived as experts and have a degree of choice over their role as carers. By the end of the twentieth century social policy makers increasingly considered carers as having needs in their own rights. Indeed, carers came to be conceptualised more in terms of their own needs as individuals than the illness, disability, or condition of their dependents.

### **The *Better Services* white papers, c.1954-1975**

The *Better Services* white papers of the early 1970s acknowledged the role of families in community care for the first time and provided a point of contention for those representing the interests of familial carers for mental disorder and those who were sceptical about the future of community care policies. Before the 1970s, policy documents relating to mental health care made little or no mention of the role of relatives in the care of the mentally ill and mentally handicapped. The report of the 1954-57 Royal Commission on the Law Relating to Mental Illness and Mental Deficiency mentioned community alternatives to hospital-based care but only implicitly mentioned the role of the family in the care of the mentally deficient and not at all for the mentally ill.<sup>14</sup> Whilst, the 1959 Mental Health Act did not explicitly mention community care, Enoch Powell's 1961 Water Tower speech and 1962

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<sup>13</sup> Julian Le Grand, 'Knights, Knaves or Pawns? Human Behaviour and Social Policy', *Journal of Social Policy*, 26:2 (1997), pp. 149-69.

<sup>14</sup> *Report of the Royal Commission on the Law Relating to Mental Illness and Mental Deficiency, 1954-1957* (London, 1957), p. 6, p. 30.

Hospital Plan referred to 'the community counterpart of the long-term hospital' without explicitly mentioning the role of families.<sup>15</sup>

The *Better Services* white papers were triggered by hospital scandals, including the scandal at Ely Hospital, Cardiff, and were the product of the findings of, Secretary of State for Health and Social Services, Richard Crossman's working group into mental health care. This section focuses on the role of special advisors to the government during the 1970s, including members of the working group, who were vocal during the decade on issues ranging from community care to the rediscovery of poverty. These left-wing special advisors were interested in structural societal changes to combat social issues and whilst tending to be sceptical of institutionalisation were also preoccupied with ensuring that the state provided adequate, alternative, care.

As explained in the Introduction to this thesis, the study of the history of community care has thus far been predominantly concerned with fleshing out the established narrative history of institutionalisation to deinstitutionalisation and community care. This process is often considered to be a distinct historical event said to have taken around forty years and begun with the Mental Health Act of 1959 and the Enoch Powell's, now infamous, 1961 Water Tower Speech.<sup>16</sup> Sociologists and social policy academics later argued that the forces behind and shaping the process from institutional to community-based provision occurred due to a variety of factors, citing, for example, economic and therapeutic driving

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<sup>15</sup> *Hansard's Parliamentary Debates*, 14 February 1962, vol. 237, cols 472-581; Roberts, Andrew, 'Enoch Powell's Water Tower Speech, 1961', 12 December 2001. <[www.studymore.org.uk/xpowell.htm](http://www.studymore.org.uk/xpowell.htm)> (12 December 2014).

<sup>16</sup> For a detailed examination of the traditional histories of deinstitutionalisation and community care see the Introduction to this thesis.



factors.<sup>17</sup> Historians have begun to rewrite the history of community care.<sup>18</sup>

Throughout the course of the second-half of the twentieth century, the concept of community care sparked considerable debate and deliberation, not least because of the imprecise nature in which it was often defined. The term 'community care' was noted as ambiguous even by some contemporaries, including president of the Society for Mental Welfare Officers, J.E. Westmoreland. In 1968 Westmoreland described the long history of the concept. "'Community care" has . . . operated in some degree for many years. Work for the mentally subnormal began largely as a community based service.'<sup>19</sup>

Indeed, community care was broader than simply the movement of long-stay patients from mental hospitals to the outside world, encompassing the care of the elderly and out-patient clinics in the community. I contend that by examining community care as both uncertain and complex richer insights can be offered to historians. In 1956 following an inquiry into National Health Service (NHS) spending, the Guillebaud Committee report proposed that domiciliary, in addition to institutional, care should be available to old people. The Guillebaud Report not only indicated that community care could mean care in your own home, but that it often referred explicitly to the care of the elderly.<sup>20</sup> Indeed, owing to demographic and structural changes, the care of the elderly was a keen driving force behind the

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<sup>17</sup> Joan Busfield, *Managing Madness. Changing Ideas and Practices* (London, 1986), pp. 236-40; Andrew Scull, *Decarceration: Community Treatment and the Deviant – A Radical View* (Cambridge, 1984), pp. 135-53.

<sup>18</sup> For instance: Bartlett and Wright (eds), *Outside the Walls*; David Skidmore, *The Ideology of Community Care* (London, 1994); Thomson, *Mental Deficiency*; Thomson, 'Sterilization'; Welshman, 'Rhetoric', pp. 204-7.

<sup>19</sup> Wellcome Library Archives and Manuscripts, The Expanding Field of Mental Health in England and Wales, 50 years of progress, 1918-1968, MS.7913/30, J.E. Westmoreland, The Development of Community Care and the Role of the Mental Welfare Officer (1968), p. 2.

<sup>20</sup> Ministry of Health, *Report of the Committee of Inquiry into the Cost of the National Health Service* (London, 1956), Cmd. 9663.

recognition of informal carers during this period, a broad category which carers for mental illness and learning disability became a part.<sup>21</sup>

During the 1960s, 1970s, and 1980s social policy makers moved towards introducing community care legislation which culminated in the 1990 NHS and Community Care Act. In the process, beginning with the white papers *Better Services for the Mentally Handicapped* (1971) and *Better Services for the Mentally Ill* (1975), the role of relatives in community care provision for mental disorder became increasingly acknowledged within social policy documentation.

The *Better Services* white papers were the direct result of Labour Secretary of State for Health and Social Services Richard Crossman's response to scandals at long-stay institutions for mental illness and mental handicap, particularly the abuse of those with mental handicaps uncovered at Ely Hospital, Cardiff in 1967, via the *News of the World* and *The Times* newspapers. In 1967 a letter appeared in *The Times* written by Barbara Robb, campaigner and founder of Aid for Elderly in Government Institutions, and was signed by supporters of legislative change including Brian Abel-Smith. A social scientist with an economics background and member of the Fabian Society, Abel-Smith became a political advisor to various Labour ministers beginning with Richard Crossman in 1968. Abel-Smith also sat on the Guillebaud committee and was instrumental in the rediscovery of poverty helping to found the Child Poverty Action Group.<sup>22</sup> The letter stated:

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<sup>21</sup> For more on old age and informal care, see: Pat Thane, *Old Age in English History: Past Experiences, Present Issues* (Oxford, 2000), pp. 129-31.

<sup>22</sup> Abel-Smith also worked closely with Richard Titmuss and Peter Townsend on the Labour Party plan for superannuation, published in 1957: Peter Townsend, 'Obituary: Professor Brian Abel Smith', *The Independent* (9 April 1996).

we have decided to collect evidence of ill-treatment of geriatric patients throughout the country, to demonstrate the need for a national investigation. We hope this will lead to the securing of effective and humane control over these hospitals by the Ministry, which seems at present to be lacking.<sup>23</sup>

As social work academic Ian Butler and social policy academic Mark Drakeford have argued, the publication of this letter in *The Times* with a complement of high profile, influential, signatories drew attention to the scandal, with several hundred letters being sent to the group with further examples of mistreatment.<sup>24</sup> Although focused on geriatric patients, the letter was also to have repercussions for the care of the mentally ill and mentally handicapped.

In June 1967 Robb published *Sans Everything: a Case to Answer*, which included responses to the initial letter in *The Times*. *Sans Everything* also referred to six other hospitals where abuse had occurred. This led Labour Minister of Health, Kenneth Robinson, to ask the appropriate Hospital Boards to set up independent Committees of Inquiry.<sup>25</sup> In 1967, whilst the enquiry was proceeding, allegations were made to the *News of the World* by a nursing assistant at Ely Hospital, Cardiff, about the treatment of patients and pilfering by staff at the hospital.<sup>26</sup> Crossman,

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<sup>23</sup> Strabolgi, Beaumont, Heytesbury, Brian Abel-Smith, Edward Ardizzone, Audrey Harvey, John Hewetson, Barbara Robb, Bill Sargent, and Daniel Woolgar, 'Old People In Mental Hospitals', *The Times*, 10 November 1965, p. 13.

<sup>24</sup> Ian Butler and Mark Drakeford, *Social Policy, Social Welfare, and Scandal: How British Social Policy is Made* (Basingstoke, 2003), pp. 29-31.

<sup>25</sup> For more information see Butler and Drakeford, *Social Policy*, p. 29-50.

<sup>26</sup> Geoffrey Rivett, *From Cradle to Grave: Fifty Years of the NHS* (London, 1998), p. 232.

who became Minister for Health in 1968, commissioned a cross-party enquiry chaired by Conservative politician Geoffrey Howe QC.<sup>27</sup>

The resultant *Report of the Committee of Inquiry into Allegations of Ill-Treatment of Patients and Other Irregularities at the Ely Hospital, Cardiff* (1969) was highly critical of institutional care for the mentally handicapped and was reported to have been leaked to the press by Crossman himself.<sup>28</sup> In response Crossman implemented more resources for hospitals for the mentally handicapped and started to reappraise plans for the provision of services for the mentally handicapped.<sup>29</sup> Crossman met with various parent and carer groups, including the Oxford and District Society for the Mentally Handicapped and the Institute of Mental Subnormality, for which he became a patron in 1972, to discuss the mental health care and the care of the mentally handicapped.<sup>30</sup> The working party, formed by Crossman to report on services for the mentally handicapped, is a prime example of the use of special advisors by the government during this period. Left-wing social campaigners who were also involved with social issues like poverty were called upon by the Labour government to help formulate policy, including economist Abel-Smith, social administration academic Richard Titmuss, and sociologist Peter Townsend.<sup>31</sup> Titmuss was a social researcher with a democratic

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<sup>27</sup> Richard Crossman's biographer, Tam Dalyell, has suggested that Crossman's interest in the elderly and mental illness came from his personal experiences, with his mother dying in a nursing home and the influence of his three wives, two of whom petitioned him to do more to help people who were mentally ill or mentally handicapped: Tam Dalyell, *Dick Crossman: A Portrait* (London, 1989), pp. 176-77.

<sup>28</sup> Dalyell, *Crossman*, pp. 178-79.

<sup>29</sup> *Ibid.*, p. 181.

<sup>30</sup> Modern Records Centre, Warwick (MRC), Papers of Richard Crossman MP (1907-1974), MSS.154/3/MH/28-32, 'Papers re. work on behalf of Mental Health, 1969-72.'

<sup>31</sup> Tom Clark, 'Peter Townsend', *Guardian*, 9 June 2009; Howard Glennerster, 'Townsend, Peter Bereton (1928-2009)' *Oxford Dictionary of National Biography*, Oxford University Press, January 2013 <<http://www.oxforddnb.com/view/article/102310>, accessed> (24 September 2013); Le Grand,

socialist view of the welfare state, who founded the discipline of social administration (now social policy) at the London School of Economics and Political Science (LSE). He was a government advisor and wrote widely on the issues of poverty and social justice. Together with Abel-Smith, social policy researcher and campaigner, Townsend was key in the 'rediscovery' of poverty in the 1960s. Townsend conducted research in the 1950s with Political and Economic Planning at the Institute of Community Studies and in Titmuss' department at the LSE (on ageing and poverty) before co-founding the Child Poverty Action Group with Abel-Smith. He campaigned for the full inspection of residential homes for the elderly, co-founded the Disability Alliance, and co-authored the 1980 *Black Report* on health inequalities. Sociologist Paul Bagguley has argued that until 1979 left-wing academics who formed the 'poverty lobby' were an important influence on policy making.<sup>32</sup>

On the advice of Howe's report, Crossman also established a body to inspect long-stay institutions in 1970. Whilst Department of Social Security (DHSS) officers had reservations about the resultant Hospital Advisory Service (HAS), the body gained the support of the medical profession.<sup>33</sup> HAS first inspected mental handicap hospitals before turning its attention to those for mentally ill and geriatric patients. HAS found that most hospitals with 1,000 or more beds had major problems.

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'Knights', pp. 149-69; A. H. Halsey, 'Titmuss, Richard Morris (1907-1973)', *Oxford Dictionary of National Biography*, Oxford University Press, 2004  
 <<http://www.oxforddnb.com/view/article/31763>> (24 September 2013);. For Richard Titmuss' view of the welfare state see: Richard Titmuss, *Problems of Social Policy* (London, 1950); Richard Titmuss, *The Gift Relationship: from Human Blood to Social Policy* (London, 1970).

<sup>32</sup> After 1979, subsequent Conservative governments favoured evidence gathered by right-wing think tanks. See: Paul Bagguley, 'Collective Action and the Welfare Recipients in Britain', in Rik van Berkel, Harry Coenen and Ruud Vlek (eds), *Beyond Marginality?: Social Movements of Social Security Claimants in the European Union* (Aldershot, 1998), pp. 39-57.

<sup>33</sup> Mary Henkel, Maurice Kogan, Tim Packwood, Tim Whitaker and Penny Youll, *The Health Advisory Service: An Evaluation* (London, 1989), p. 9; Rivett, *From Cradle*, p. 233.

Reactive to changing government concerns, it shifted its focus to community care from 1976.<sup>34</sup> Additional committees of enquiry were later established because of further scandals breaking in the early 1970s, centred on Farleigh Hospital, Somerset, and Whittingham Hospital, Preston.<sup>35</sup>

*Better Services for the Mentally Handicapped* was published in 1971 by new Conservative Secretary of State for Social Security, Sir Keith Joseph. Rather than exclusively focusing on institutional care of mental handicap, the subsequent white paper asserted that non-medical community based services, in the form of hostels, schools, and training centres would be preferable to hospital-centred care. This is unsurprising given the scandals and that deinstitutionalisation was already in progress. The Institute of Mental Subnormality was founded in response to and in support of the white paper and council members included representatives from relevant non-governmental organisations and medical bodies. The Institute aimed to 'raise the standard of every aspect of treatment and care for the mentally subnormal and this will include improvement of their medical, nursing, social, educational and environmental needs'.<sup>36</sup> The white paper was not, however, considered satisfactory by Crossman's working group. Townsend explained in an article in the *Sunday Times* on 27 June 1971 that he wanted hospital provision for the mentally handicapped to be phased out completely, instead preferring

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<sup>34</sup> Henkel, Kogan, Packwood, Whitaker and Youll, *The Health Advisory Service*, pp. 10-11; Rivett, *From Cradle*, p. 233.

<sup>35</sup> Rivett, *From Cradle*, p. 233-34. After 1967 the DHSS was quick to act when they became aware of potential problems so few scandals became public after this time: Rivett, *From Cradle to Grave*, p. 235. Regional Advisory Teams were established and published reports, for example the South East Metropolitan Regional Hospital Board's report: Regional Advisory Team, *But for the Grace . . .: The Long-Stay Hospitals: Mental Handicap, A Report* (Croydon, 1973).

<sup>36</sup> MRC, MSS.154/3/MH/28-32, 'Papers re. work on behalf of Mental Health, 1969-72'.

accommodation to be made available in small houses resembling private housing.

The white paper also mentioned another locus of care, the family home:

Most parents are devoted to their handicapped children and wish to care for them and to help them to develop their full potential. About 80 per cent of severely handicapped adults - and a higher proportion of the most mildly handicapped - live at home. Their families need advice and many forms of help, most of which are at present are rarely available.<sup>37</sup>

As will be examined in Chapter Four of this thesis, the high instance of those with mental handicaps living in the family home was due to a range of factors, including: the notion that the family environment was beneficial for the development of handicapped children; that severely mentally handicapped children had been deemed 'ineducable' by the 1944 Education Act; and due to long waiting lists for institutional places.<sup>38</sup> Social policy academic Liam Concannon has noted that by recognising the role of the family in care 'this was a turning-point in that the literature from here begins to describe the family in terms of the *caring family* and the *main source of care*.'<sup>39</sup>

*Better Services for the Mentally Ill* was published in 1975 by Joseph's successor as Secretary of State for Social Services, Labour MP Barbara Castle. The white paper was more tempered in its support of community-based solutions,

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<sup>37</sup> DHSS, *Better Services* (1971), p. 4.

<sup>38</sup> Education Act, (London, 1944), pp. 45-47; Vicky Long, "'Often there is a Good Deal to be Done, But Socially rather than Medically': The Psychiatric Social Worker as Social Therapist, 1945-70", *Medical History*, 55:2 (April 2011), p. 235.

<sup>39</sup> Liam Concannon, *Planning for Life: Involving Adults with Learning Disabilities in Service Planning* (London, 2005), p. 40.

proposing that local services needed to be in place before hospitals closed and that for this to happen the economic situation would need to be improved.<sup>40</sup> The 1975 white paper also made reference to the role of relatives, stating that: 'in reality those in the community most involved in the care of the mentally ill are usually their families'. The document also acknowledged the impact of care on families, although it did not go into specifics on this point: 'the implications of mental illness for the family when it is prolonged, are far reaching'.<sup>41</sup>

Although triggered by institutional abuse scandals, like that at Ely Hospital, the *Better Services* white papers not only included families in the range of those providing care but in fact suggested that relatives were one of the major care-givers in the early 1970s. This is not surprising given the combination of the white papers' tendencies to criticise institutional care, in light of deinstitutionalisation agendas and abuse scandals, and the argument that community services were currently inadequate and required more funding. Thus, familial care came to prominence within these documents as a by-product of a consideration of whether community care was preferable to institutional provision in the care of the mentally handicapped and the mentally ill.

With changes to education policy, moves towards deinstitutionalisation of the mentally ill and mentally handicapped, and concerns over an ageing population, questions were raised over who would, could, or should provide care. These discussions were sped up by the hospital scandals that began to emerge between 1967 and 1969. On 12 July 1971, Conservative Secretary of State for Social Services, Sir Keith Joseph announced to the House of Commons that 'there is no doubt that

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<sup>40</sup> Rivett, *From Cradle*, p. 236-37.

<sup>41</sup> DHSS, *Better Services* (1975), p. 28.



the occasional scandal does an enormous amount for a social service'.<sup>42</sup> Yet, whilst the *Better Services* white papers emerged as a result of the Ely Hospital scandal their content was, in part, based on research which had already been underway during the 1960s.<sup>43</sup> In this sense the hospital scandals gave an impetus for the state to act more quickly on the issue of mental health care reform. Numerous enquiries noted problems with long-stay hospitals, but also began to acknowledge short-falls in community based provision. This in turn led to a growing awareness and acknowledgement of the role of relatives in care, an area which had already begun to be researched by social scientific researchers interested in a range of issues, including changing community patterns and the epidemiology of schizophrenia.<sup>44</sup>

The *Better Services* white papers spoke very directly to the community care agenda and gave the DHSS an opportunity to consider what community care for mental handicap and mental illness would look like in reality. However, these proclamations also gave sceptics an opportunity to speak out about their concerns over the place of families in community care provision. Indeed, throughout the remainder of the 1970s and the 1980s debates took place not only about the nature of community care services but in fact the very essence of what 'community care' meant. These debates were contributed to by parent and carer groups concerned about the implications that new community care legislation would have

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<sup>42</sup> *Hansard's Parliamentary Debates*, 12 July 1971, vol. 821, cols 35-98.

<sup>43</sup> Ray Jones has made a similar observation for the emergence of new legislation for children in the wake of tragedy and scandal: Jones, 'Children Acts', p. 48.

<sup>44</sup> For further analysis of this social scientific research see Chapter Two of this thesis.

on the families of the mentally ill and mentally handicapped. For example, the NSF expressed concern over a service gap in the wake of widespread hospital closures.<sup>45</sup>

### **The Invalid Care Allowance, c.1971-1986**

The world's first Minister for the Disabled, Labour politician Alf Morris was appointed in 1974. Prior to this Morris had introduced a bill into Parliament, the Chronically Sick and Disabled Persons Act (1970), which recognised disabled people and gave them rights. Morris had personal experience of disability. His father died from an illness related to his exposure to gas during the First World War, after which his mother was denied a widow's pension.<sup>46</sup> Following Morris' appointment, the Family Fund was established in 1975. The Fund was set up to provide financial assistance to the families of thalidomide children, but also other families with a handicapped child. A year later in 1976, the Invalid Care Allowance (ICA) was introduced.<sup>47</sup> The ICA was the first benefit introduced to directly remunerate carers in England and Wales. Although a significant step towards state recognition of the care provided by family members of relatives with severe disabilities, the legislation proved controversial sparking opposition from married women's groups, second-wave feminists, and leading to the inception of the Association of Carers in 1981, the first organisation representing all carers regardless of age and sex. The

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<sup>45</sup> The Wellcome Library, Dorothy Silberston, and the National Schizophrenia Fellowship, 1970-2004, PP/DSI/C/1/14, National Schizophrenia Fellowship Publications, 1970s-1980s, *Cart Before the Horse? The correspondence between the Chairman of the National Schizophrenia Fellowship and the Minister for Health* (February 1984 - July 1985).

<sup>46</sup> Andrew Roth, 'Lord Morris of Manchester: Obituary', *Guardian*, 14 August 2012.

<sup>47</sup> Department of Health and Social Security, The Social Security (Invalid Care Allowance) Regulations (1976), No. 409.

introduction of the Invalid Care Allowance, then, put family care-givers for the severely disabled on the social policy agenda and provided those campaigning for the interests of carers of those with mental illnesses and mental handicaps, including carer organisations and medical professionals, a platform and specific issue to discuss and challenge.

The foundations of the post-war social security system were laid by the Beveridge Report in 1942. The plan, which aimed to combat the 'five giants' of Want, Disease, Ignorance, Squalor, and Idleness, was based on an assumption of universal entitlement but only within the bounds of a society in which male breadwinners worked full time to support their wives who would care for the family and home.<sup>48</sup> However, as historian Pat Thane has argued, 'the 1930s to 1950s was . . . the only age, of the near universal, stable, long-lasting marriage, often considered the normality from which we have since departed.'<sup>49</sup> The 1950s and 1960s were also atypical in terms of their low unemployment rates, averaging about two and a half per cent.<sup>50</sup> By the 1970s British society had begun to change in terms of both demographic structures, with an ageing population and decreasing marriage rates, and also changes to the labour market.<sup>51</sup> These changes

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<sup>48</sup> Karen Rowlingson, "'From Cradle to Grave': Social Security over the Life Cycle', in Jane Millar (ed.), *Understanding Social Security: Issues for Policy and Practice* (Bristol, 2003), p. 12.

<sup>49</sup> Pat Thane, 'Family Life and "Normality" in Postwar British Culture' in Richard Bessel and Dirk Schumann (eds), *Life After Death: Approaches to a Cultural and Social History during the 1940s and 1950s* (Cambridge, 2003), p. 198.

<sup>50</sup> Stephen Nickell, 'Unemployment in Britain', in Paul Gregg and Jonathan Wadsworth (eds), *The State of Working Britain* (Manchester, 1999), p. 21.

<sup>51</sup> April Gallwey, 'Lone Motherhood in England, 1945-1990: Economy, Agency, and Identity (PhD Thesis, University of Warwick, 2011); Katherine Holden, 'Family, Caring and Unpaid Work', in Ina Zweiniger-Bargielowska (ed.), *Women in Twentieth-Century Britain* (Harlow, 2001); Kathleen Kiernan, Hilary Land and Jane Lewis, *Lone Motherhood in Twentieth-Century Britain: From Footnote to Front Page* (Oxford, 1998); Pat Thane, 'Family Life and "Normality" in Postwar British Culture', in Richard Bessel and Dirk Schumann (eds), *Life After Death: Approaches to a Cultural and Social History of Europe during the 1940s and 1950s* (2003); Pat Thane, *Old Age in English History: Past Experiences, Present Issues* (Oxford, 2000).

necessitated gradual revision to welfare state provision. This had implications for both mental health care and informal care. Significant to this rethinking was the emergence of numerous and varying social movements in the 1970s. As the state began to reconsider social policy provision, interested parties, including second-wave feminists and service-users, were primed and eager to contribute to the debate. As such, I argue that the changes to British society in the 1970s, whether real or perceived, led not only to new legislation in the arena of social welfare policy, but also coincided with the mobilisation of an engaged public who were keen to take part in the debate and to attempt to secure what they felt they were entitled to from the state.<sup>52</sup> During this process the category of the carer became significant as it sat at the intersection between demographic and employment shifts and drew the concern of feminist campaigners and those associated with carer organisations.

The Invalid Care Allowance was introduced following a campaign from the National Council for Single Women and her Dependents (NCSWD), which had already contributed to the introduction of the 1971 Attendance Allowance, a benefit available to those needing constant care at home. Established in 1965, two of the NCSWD's founder members were Conservative politician Sir Keith Joseph and Liberal Party president Nancy Seear, then a lecturer at the LSE. This followed publicity generated when the Reverend Mary Webster was interviewed by, and wrote a letter to, the *Guardian* in early 1963 regarding the need to support single women with dependants, a call which came from her own experience of struggling

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<sup>52</sup> Le Grand, 'Knights', pp. 149-69.

to care for her aged mother whilst also earning a living.<sup>53</sup> The NCSWD was focused on the care of the elderly, changing its name to The National Council for Carers and their Elderly Dependents on 6th September 1983. However, the introduction of ICA was not only a result of those campaigning for improvements in the care of the elderly. ICA was introduced following the *Better Services* white papers which increased awareness of the role of the family in mental health care.

Another factor was the media attention associated with the Thalidomide scandal.<sup>54</sup> Between 1957 and 1962 expectant mothers in Britain had been recommended thalidomide, a drug marketed as being safe, to combat the symptoms of morning sickness. Thalidomide babies had been born with 'stunted flipper-like extremities with missing fingers, and an absence of the proximal portion of the limb, or absence of entire limbs . . . Many infants also had affected internal organs'.<sup>55</sup> The parliamentary debate on the Thalidomide Children in November 1972 provided an opportunity for politicians to raise concern over the plight of familial carers of mental handicap and mental illness more broadly, leading most directly to the establishment of the Family Fund in 1973.<sup>56</sup> For instance, Alf Morris stated: 'the thalidomide children are a symbol of the very much larger number of severely disabled children.'<sup>57</sup>

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<sup>53</sup> May Abbot, 'Single and Silent', *Guardian*, 4 January 1963, p. 6; R. Mary Webster, 'Over Forty: Letters to the Editor', *Guardian*, 8 March 1963, p. 8.

<sup>54</sup> Claire Sewell, '"If one member of the family is disabled the family as a whole is disabled": Thalidomide Children and the Emergence of the Family Carer in Britain, c. 1957 to 1978', *Family and Community History* (forthcoming, 2015).

<sup>55</sup> Stefen Timmermans and Valerie Leiter, 'The Redemption of Thalidomide: Standardising the Risk of Birth Defects', in Thomas Schlich and Ulrich Tröehler (eds), *The Risks of Medical Innovation: Risk Perception and Assessment in Historical Context* (Abingdon: 2006), p.264.

<sup>56</sup> *Hansard's Parliamentary Debates*, 29 November 1972, vol. 847, cols 432-510.

<sup>57</sup> *Ibid.*

The Invalid Care Allowance was introduced in 1976 as part of the broader Social Security Act (1975). The Allowance was the first benefit of its kind, specifically aimed at carers, not only to be introduced in Britain but across the world.<sup>58</sup> The Social Security Act set out that a person was entitled to the allowance if they were 'regularly and substantially engaged in caring for that person' with a severe disability, which was refined in a document from 1976 setting out regulations to be at least thirty-five hours a week of care.<sup>59</sup> Available only to those able to demonstrate that they were full time carers, the payments were low, with less money being given for the care of child dependants, thus claimants' payments needed to be supplemented by additional Income Support.<sup>60</sup> By being available to those caring for someone with a severe disability, ICA conflated care for the elderly who had disabilities with the care for severe physical and mental disabilities in children and adults. From this point forward, familial care for mental illness and mental handicap was often included in legislation for the elderly, which, in light of concerns over the ageing population, was of keen concern for contemporaries.

ICA was available to both men and women, but significantly married women (who were living with or maintained by their husbands), non-relatives, those in full-time education or employment, and those under the age of sixteen were excluded from claiming the benefit. The National Insurance Advisory Committee maintained that this decision was made with an understanding that although many married

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<sup>58</sup> Report of the National Insurance Advisory Committee in accordance with section 139(3) of the Social Security Act 1975, 271, 1975-76 (London, 1976), p. 23.

<sup>59</sup> DHSS, *Social Security Act* (London, 1975), Chapter 14, p. 4; Report of the National Advisory Committee, p. 25.

<sup>60</sup> Michael Hill, *Social Security Policy in Britain* (Aldershot, 1990), p. 70.

women were providing care, particularly for children and elderly parents, the committee wanted to:

Concentrate the resources that were available on the group which, in general, faced the severest difficulties, i.e., the single women and the men who have had been compelled by the need to care for a severely disabled relative to give up all thoughts of paid employment . . .<sup>61</sup>

The decision to exclude married women from those able to qualify for the benefit was based on the rationale that 'where a wife is looking after a severely disabled husband, he will almost certainly qualify for invalidity benefit with which there can be paid a dependency benefit for his wife (and for any dependent children)'.<sup>62</sup> ICA was eventually extended to married women following in a European Court ruling in 1986 following a considerable amount of discussion, debate, and controversy in the national press, among carers themselves, and by second-wave feminists.

In 1994 social policy academics Julia Twigg and Karl Atkin listed feminism as one of the main strands in debates from the 1950s onwards about the nature of informal care. The other strands that Twigg and Atkin referred to were sociological scholarship on the theme of kinship from the 1950s and 1960s; literature on burden and stress; the New Right critique of community care; and the disability lobby.<sup>63</sup> Twigg and Atkin argued that whilst academic interest in familial obligations to provide care were present in sociological work on kinship in the 1950s and 1960s,

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<sup>61</sup> Report of the National Advisory Committee, p. 25.

<sup>62</sup> Ibid., p. 25.

<sup>63</sup> Julia Twigg and Karl Atkin, *Carers Perceived: Policy and Practice in Informal Care* (Buckingham: 1994), pp. 2-6.

particularly the work of the Institute of Community Studies, it was not until the 1970s and 1980s that normative views of the family present within this work were challenged.<sup>64</sup> As awareness grew of changes both in terms of the number of women active in the labour market and in familial structure from the 1970s, with higher divorce rates and greater instances of lone motherhood, the male breadwinner model became increasingly challenged in and irrelevant to post-war British society. The male breadwinner model was based on an assumption that men were the primary wage earners and women the primary care-givers. It was built into the post-war settlement and the key principles of the welfare state. As social policy academic Jane Lewis has asserted, however, women's engagement in the labour market was not simply a post-war phenomenon. Indeed, Lewis argued for the atypicality of the rigid distinction between male and female roles after the Second World War.<sup>65</sup> Working on an ethos of 'the personal is political', some post-war feminists asserted that women utilised the welfare state more than men. As women were the predominant carers in the kinship group, welfare had more of a direct impact on their personal lives. However, women were given less of a say in how the welfare budget was spent and received lower wages than men. This, feminists argued, demonstrated women's unequal status to men in terms of both family and work.<sup>66</sup>

In this context, some feminists began to reconsider and strongly critique not only traditional conceptualisations of the family, but also community care. At the intersection of these two interrelated concerns was women's role in unpaid labour,

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<sup>64</sup> Ibid., p. 2.

<sup>65</sup> Jane Lewis, 'The Decline of the Male Breadwinner Model: Implications for Work and Care', in *Social Politics*, 8:2 (2001), pp. 153-55.

<sup>66</sup> Jennifer Dale and Peggy Foster, *Feminists and the Welfare State* (Abingdon, 2013), pp. ix-x.



including informal care. Feminists, who were actively engaging with the social policy making process, 'in which the position of women was assumed and unchallenged', were particularly vocal about the Invalid Care Allowance.<sup>67</sup> Considering prevalent and persistent views of the family and community care to be based on the supposedly natural role of women as unpaid carers, feminists campaigned for the ICA to be extended to married women as part of a much broader equal opportunities agenda. As Twigg and Atkin have argued, feminists not only viewed this in terms of women's access to the labour market, but also in relation to women's tendency to self-identify as carers.<sup>68</sup> As a social security policy available only to (some) carers of the severely disabled, feminist attention was also drawn to issues related to the familial care of mental illness and mental handicap, which served to highlight the particularities of this form of informal care. This coincided with growing interest among social scientific researchers into the familial care of mental illness and mental handicap, which will be examined in Chapter Two of this thesis.

In 1983 social policy academic Fran Bennett explained how the feminist reaction to ICA revealed tensions within feminist argument:

Feminists have not argued against the extension of invalid care allowance on the grounds that this would be paying women to stay at home. Yet we would expect these arguments to be advanced automatically if the government suggested wages for full-time child-care by mothers.<sup>69</sup>

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<sup>67</sup> Twigg and Atkin, *Carers*, pp. 2-3.

<sup>68</sup> *Ibid.*, p. 3.

<sup>69</sup> Fran Bennett, 'The State, Welfare, and Women's Dependence', in Lynne Segal (ed.), *What is to be done about the Family?* (Harmondsworth, 1983), p. 206.

With this in mind, feminist academics Jennifer Dale and Peggy Foster asserted that in their view, during the 1980s the acceptance amongst feminists of social policy changes was dependent on whether the change was imposed from above or secured as a result of feminist struggle.<sup>70</sup> Feminist sociologist Janet Finch made a related argument that when the state posited that families, and in particular women, should provide care it was often prescriptive rather than descriptive.<sup>71</sup> Thus, despite vehemently opposing a state wage for women to remain at home and care for their families, fearing that this would further cement supposedly traditional gender roles, feminists were in support of the extension of ICA to married women. Recognising the difference between familial care in general and familial care for those with severe disabilities in particular, the feminist position on ICA demonstrates the extent to which the introduction of this legislation made people aware of the role of women in the care of disability.<sup>72</sup> The issue of financial support for carers triggered debate and captured the imagination of the national press in Britain. Whilst discussions about, and changes to, the ICA had an impact on relatives caring for mentally ill or mentally handicapped relatives, the media largely focused on the care of the elderly, presumably because this issue was more publicly prominent and potentially affected a wider readership.

The NCSWD was predominantly conservative in outlook and focused on single women. Although the NCSWD opposed the extension of ICA to married women, in 1986 the government revised the legislation following a European

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<sup>70</sup> Dale and Foster, *Feminists*, pp. 129-30.

<sup>71</sup> Finch, *Family*, p. 237; Finch and Mason, *Negotiating*, p. 166.

<sup>72</sup> For example see the following article which focuses on the care of senile dementia in the home, see: Jane Lewis, 'Who Really Cares about Home Care?', *The Times*, 29 May 1987, p. 12.

Economic Community ruling that the existing ICA legislation breached their directive that social security systems should be based on equality. It is thought that the NCSWD's opposition to the extension of the ICA was based on reports that Secretary of State for Social Security, Norman Fowler, would abolish the benefit rather than extend it to married women.<sup>73</sup>

The test case for this legislative change was Jackie Drake, a member of the Association of Carers which had been founded in 1981 by Judith Oliver. A mother and carer for a disabled husband, Oliver wanted the Association of Carers to represent all carers, regardless of age and sex, and to ask carers directly what their needs were. The Association aimed 'to assist and support anyone who is leading a restricted life because of the necessity to care for a person who is mentally or physically handicapped or ill or impaired by infirmity.'<sup>74</sup> Initially funded by an Equal Opportunities Commission grant, the Association of Carers worked on the ethos that 'carer' should be self-defined by carers themselves.<sup>75</sup> Although founded later than carer groups in the mental health field, the broad platform and targeted policy aims of the Association of Carers helped to raise the profile of family care-givers.

When the ICA was discussed in feminist literature, academic scholarship, and the media, there was an underlying assumption that informal care of the disabled was provided by women. This is understandable given that the debate was focused on one of the groups that could not directly access ICA payments: married women. However, despite feminist assertions that women should not be barred from obtaining a wage because they were providing informal care, a role which

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<sup>73</sup> Tim Cook, *The History of the Carers' Movement* (London, 2007), p. 37.

<sup>74</sup> Ibid., p. 36.

<sup>75</sup> Ibid., pp. 35-36.

feminists thought should be provided by the state, they were unwilling to, or perhaps more accurately unconcerned with, acknowledging the role of men in the informal care of severe disabilities, including mental illness and mental handicap.<sup>76</sup>

Researchers at the Social Policy Research Unit (SPRU) at the University of York, who were predominantly women, became heavily involved in researching informal care, particularly in the 1980s and early 1990s. Established in 1973 under the directorship of Professor Jonathan Bradshaw, the independent SPRU aimed to conduct research into health and social care with a view to developing associated social policy. The SPRU's research was frequently published as reports by the Department of Social Security. The SPRU's initial analysis of the results of the 1985 General Household Survey section on Informal Care referred to the epidemiology of carers and spoke of the 'risks' of becoming a carer. In addition, the report uncovered a surprising number of male carers challenging assumptions that caring was 'almost exclusively a women's issue'.<sup>77</sup> Although secondary analysis by SPRU researchers' Gillian Parker and Dot Lawton found that most of the male care-givers were spouses and / or were engaged in lighter caring activities than their female counterparts, the General Household Survey still challenged long-held feminist assumptions about the gendering of care.<sup>78</sup> Dale and Foster have suggested that by focusing on personal concerns feminists tended to see 'carers solely as daughters and daughters-in-law'. Yet, far from invalidating feminist theories of welfare state

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<sup>76</sup> Twigg and Atkin, *Carers*, p. 3.

<sup>77</sup> Atkin, *Carers*, p. 3.

<sup>78</sup> Gillian Parker and Dot Lawton, *Further Analysis of the 1985 General Household Survey Data on Informal Care. Report 4: Male Carers*, (York, 1985), pp. 1-3.

provision, Dale and Foster argued that feminist critique remained 'sophisticated', merely needing to consider extra dimensions.<sup>79</sup>

The male breadwinner model and the welfare state were based on the proviso of full employment, which in the 1940s meant full male employment. In order for men to claim ICA benefit they could not be over sixty-five or in either full time employment or education. ICA payments were only available to those providing over thirty-five hours of care a week. In addition, the benefits were often too meagre to support claimants without supplementary income support payments. It could, therefore, be difficult for men to become informal carers, in the sense recognised by the ICA. In 1985 NSF member Philip Wilmot, who later became the organisation's chairman, described his experience of having a daughter with schizophrenia:

My daughter was a social worker, my son is a General Practitioner and my daughter-in-law a psychiatrist. I have had many experiences in procuring treatment for my daughter in England and Switzerland. I retired early to give closer support for my daughter and am concerned to give help to other relatives in less fortunate circumstances.<sup>80</sup>

This is an example of a male carer who was financially secure enough to take early retirement so that he could spend more time caring for his daughter who had schizophrenia. The extract is taken from Wilmot's successful nomination to become

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<sup>79</sup> Dale and Foster, *Carers*, pp. 4-5.

<sup>80</sup> The Wellcome Library, Dorothy Silberston, and the National Schizophrenia Fellowship, 1970-2004, PP/DSI/A/3/1, Annual General Meetings Minutes and Papers, 1979-2002, *AGM Minutes* (24 October 1985), p. 4.

NSF chairman. Wilmot considered his retirement a choice he was able to make, acknowledging that others less privileged were not in a position to choose between working and caring. Indeed, in 1996 seventy-six per cent of the 357,000 recipients of ICA payments were women.<sup>81</sup>

In spite of the focus of campaigns by feminists and the media coverage on the extension of ICA to married women, others argued that ICA did not go far enough and did not provide the type of support that carers needed. Family care-givers of those with severe mental illnesses and mental handicaps did not need to provide thirty-five hours of care a week, or to make care-giving their primary activity, in order for their lives to be affected. In 1973 Dorothy Silberston, mother of a schizophrenic daughter and NSF Parliamentary Officer, explained her plight in an anonymised evidence document to Sir Keith Joseph: 'K [sic] before the illness was someone we were delighted to have at home – now she is a threat to our lives, someone we dread hearing on the telephone, wondering what the latest disaster is'.<sup>82</sup> Remuneration for providing care to relatives did little to combat the emotional effects of having a relative with a mental illness or mental handicap. Carer groups attempted to negotiate the category of the carer and provide evidence to politicians based on its members' experiences of caring, arguing that financial assistance in isolation was not enough. On 25 October 1969 Pauline Holroyd, Honorary Secretary of the Oxford and District Society for the Mentally Handicapped and Occupational Therapist at a mental hospital, wrote to Minister for Health, Richard Crossman, stating: 'human wretchedness cannot be measured in hard cash,

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<sup>81</sup> Stephen McKay and Karen Rowlingson, *Social Security in Britain* (Basingstoke, 1999), p. 108.

<sup>82</sup> WL, PP/DSI/B/2, Miscellaneous NSF Policy Papers, 1970-2001, *D. Silberston provides evidence for Sir Keith Jones* (December 1973), p. 11.

and families in greatest need may be among the least likely to be helped. i.e. short term hostel care not available for the most severely handicapped.<sup>83</sup> Ten years later in 1979, social work academics Jonathan Bradshaw and Dorothy Lawton made a similar point, stating that: 'to attempt to relieve . . . stress by providing goods, services, cash or, indeed, any resources is bound to fail. It appears that relief of emotional stress may not be a feasible aim of public policy'.<sup>84</sup>

ICA, and the subsequent controversy and debate that surrounded its introduction, demonstrated the extent to which familial care became politicised in the 1970s and 1980s. As ICA was available to those caring for relatives with severe disabilities, the Allowance served to highlight the more specific phenomenon of familial care of mental illness and mental handicap. ICA's introduction, and the controversy and debate that it sparked, illustrated the range of interest groups that were concerned with the place of the carer within the community care agenda. Reaction to ICA legislation expanded the perception of carers to not only be single women but to also include married women, and men. State assistance, up until this point, had been predominantly financial; however, as concern for the well-being of care-givers themselves grew there were calls for more holistic support and training for this group.

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<sup>83</sup> Modern Records Centre, Papers of Richard Crossman MP (1907-1974), MSS.154/3/MH/5-6, Correspondence and Subject Files, Papers re. work on behalf of Mental Health, 1969-1972, *Letter from Pauline Holroyd to Richard Crossman* (25 October 1969).

<sup>84</sup> J. Bradshaw and D. Lawton, 'Tracing the Causes of Stress in Families with Handicapped Children' *British Journal of Social Work*, 8:2, (1978), p. 189.

## Contesting Community Care, c. 1983-1990

In 1983 businessman Sir Roy Griffiths was commissioned by Conservative Prime Minister Margaret Thatcher to embark on a report to recommend a broad sweeping overhaul of the National Health Service. The resultant report was published in 1988 and entitled *Community Care: Agenda for Action*. Commonly referred to as the *Griffiths Report*, the report made recommendations about the future of community care and influenced the NHS and Community Care Act (1990). The *Griffiths Report* and the NHS and Community Care Act included familial carers for people with mental illnesses and learning disabilities, but the definition was broad, also encompassing carers for the elderly and the chronically ill.

The *Griffiths Report*, which recommended that community care be administered by local authorities, triggered a great deal of response from those with an interest in the future of health care, and indeed the place of the familial carer for mental illness and mental handicap within it. During the 1980s family carers were frequently referred to as informal carers. Indeed, the *Griffiths Report* and the *Caring for People* white paper (1989) posited informal carers as one of the main providers of community care. The carer in these pieces of social policy also referred to carers of the elderly and whilst my focus here will be on carers for mental disorder it is important to note that, as with the Invalid Care Allowance, an important consideration and driving force behind these social policy documents was concern over the issue of an ageing population.

During the 1960s, 1970s, and 1980s social policy makers attempted to introduce community care legislation which culminated in the NHS and Community



Care Act (1990). Beginning with the *Better Services* white papers in the early 1970s the role of the carer in community care provision became increasingly acknowledged. However, as a principle component of the future of mental health care, and social welfare more broadly, community care lacked both coherence and clarity. This led to concern among those interested in the plight of family carers of mental disorder that community care would in reality mean care *by* families. Whilst families had cared for ill or disabled relatives for centuries, this role was not a legal imperative and could be supplemented by institutional care at times of crisis or when families could not, or would not, perform this caring role.<sup>85</sup> However, the vagueness of community care rhetoric, not only caused concern for those championing the familial carer, but also offered an opportunity for and a space in which interested parties could negotiate the place of the carer in future mental health and community care policy and service provision.

Griffiths had been commissioned by conservative Prime Minister Margaret Thatcher in 1983 to write a report on the National Health Service, which Thatcher hoped would provide recommendations to help cut costs and move towards privatisation in the provision of community care. Following his knighthood in 1985 Griffiths produced a green paper on community care which was published in 1988. The *Griffiths Report* argued that community care had thus far been under-funded, rather than proposing ways to further cut spending.<sup>86</sup> The report posed the question 'what is community care?'. The report referred to the division between

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<sup>85</sup> John K. Walton, 'Casting Out and Bringing Back in Victorian England: Pauper Lunatics, 1840-70', in W.F. Bynum, Roy Porter and Michael Shepherd (eds), *The Anatomy of Madness: Essays in the History of Psychiatry, Vol. 2: Institutions and Society* (London, 1985), pp. 132-46.

<sup>86</sup> Pat Thane, 'Memorandum Submitted to the House of Commons' Health Committee Inquiry: Social Care', *History and Policy*, October 2009.  
<[http://www.historyandpolicy.org/docs/thane\\_social\\_care.pdf](http://www.historyandpolicy.org/docs/thane_social_care.pdf)> (17 December 2014).

health and social services departments, stating that 'community care is a poor relation: everybody's distant relative but nobody's baby'.<sup>87</sup> For Griffiths, effective community care was, partly at least, a matter of proximity and relationships: 'families, friends, neighbours and other local people provide the majority of care in response to needs which they are uniquely well placed to identify and respond to.' Griffiths suggested that consultation of carers' needs and providing more appropriate services were key to maintaining what he considered to be 'the primary means by which people are enabled to live normal lives in community settings.'<sup>88</sup> Griffiths recommended that more support be offered to families to help 'maintain the role of the family carer', via providing information about available services and accounting for their views and wishes.<sup>89</sup>

During the consultation period for the green paper and following its publication interested groups, including the NSF, attempted to influence the paper's findings, recommendations, and outcomes to try and ensure that the interests of informal carers were borne in mind. These interested parties turned their attention to what community care meant. For example, the 1984 report of *The House of Commons Social Services Committee on Community Care with Special Reference to Adult Mentally Ill and Mentally Handicapped* chaired by Labour MP Renee Short stated that the term community care was virtually meaningless. The report also expressed concern that 'any fool can shut a mental hospital' and 'racing

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<sup>87</sup> DHSS, *Community Care*, p. iv.

<sup>88</sup> *Ibid.*, p. 5.

<sup>89</sup> *Ibid.*, pp. 6-7.

ahead and damning the consequences has to stop.'<sup>90</sup> The NSF summarised the *Griffiths Report* for its members whilst also providing a critique. Although 'in complete agreement with most of the recommendations of the report', it also urged the government to 'plan intelligent alternatives to our mental hospitals, and provide the money for them, demonstrate that they can be as good or better, and get them going *ahead* of discharging yet more patients to a limbo of poor or non-existent "community" services'. The NSF criticised the report for suggesting that the term community care was meaningless, whilst also stating that: 'we wholeheartedly support a policy of community care for mentally disabled people.'<sup>91</sup> The NSF also made the recommendation that the term 'individual care' would be more appropriate than the term community care.

The lack of clarity over the term 'community care' was also highlighted in 1986 by sociologist Peter Willmott who proposed a multi-faceted definition of the government policy. Willmott, who had previously been a research assistant for the Labour Party and one of the founder members of the Institute of Community Studies, joined the Policy Studies Institute in 1983. Willmott often worked collaboratively with his wife, social researcher, Phyllis Mary Noble and they were particularly interested in the family, poverty, and inner city life.<sup>92</sup> Willmott argued that community care could be defined firstly as 'care other than that in a hospital or an institution'; secondly as 'a more positive version of the first, covering all the care given "in the community" . . . from the full range of sources including informal'; and,

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<sup>90</sup> WL, PP/DSI/C/1/13, National Schizophrenia Fellowship Publications, 1970s-1980s, *Comments on the House of Commons Social Services Committee Report on Community Care with Special Reference to the Adult Mentally Ill and Mentally Handicapped*, p.2.

<sup>91</sup> WL, PP/DSI/C/1/13, *Comments*, p. 2, p. 6.

<sup>92</sup> Michael Young, 'Willmott, Peter (1923–2000)', *Oxford Dictionary of National Biography*, (Oxford, 2004).

thirdly as voluntary and informal 'care by the community'.<sup>93</sup> Willmott indicated that 'there remains a good deal of confusion in official circles', suggesting a lack of consensus over the meaning of community care by those involved in the social policy making process.<sup>94</sup>

The drafting of the *Griffiths Report* offered scope for community care to be enacted in ways which would benefit or hamper the lives of caring relatives. It is therefore unsurprising that carer groups demonstrated a keen interest in social policy related to community care at this time. The NSF was particularly keen to air its grievances and influence policy decisions, given their belief that without adequate community services in place when hospitals were closed, previous long-stay patients, and in particular those with schizophrenia, would end up on the streets or in prison rather than in their familial home.<sup>95</sup> Social psychiatrist and medical advisor to the NSF John Wing thought that psychiatric hospitals needed to be reformed, but was worried that hospital closures would mean there would not be enough hospital beds for those that needed them, especially without adequate rehabilitation services in the community.<sup>96</sup>

In 1984 the NSF, along with the Richmond Fellowship, and with the support of the Psychiatric Rehabilitation Centre, the St. Mungo Community Trust, and the Salvation Army, sent a statement on hospital closures and community care to the Secretary of State for Social Security and the Minister for Health. The Conservative

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<sup>93</sup> Willmott, *Social Networks*, p. 5.

<sup>94</sup> Simon Goodwin, *Community Care and the Future of Mental Health Service Provision* (Aldershot, 1990), pp. 1-4; Willmott, *Social Networks*, p. 5.

<sup>95</sup> WL, PP/DSI/A/4/1, Annual Reports and Accounts and Annual Reviews, *Schizophrenia. A Time for Action. Annual Report, 1985-86*, p. 3.

<sup>96</sup> Vicky Long, 'Rethinking Post-War Mental Health Care: Industrial Therapy and the Chronic Mental Patient in Britain', *Social History of Medicine*, 26:4 (2013), p. 746.

Minister for Health, Kenneth Clarke, responded inviting the NSF to the House of Commons to discuss the future of schizophrenia care with him. This led to a series of correspondence between the two parties. Feeling that the contents of these letters was of relevance to those with schizophrenia, their relatives, professional health service and social workers, the NSF published the correspondence, along with a commentary, in a pamphlet entitled 'Cart Before the Horse?' (1985).<sup>97</sup> This is an example of a group interested in the place of the family carer in mental health care not only lobbying government, but also successfully opening up a dialogue with a relevant Minister.

In parliamentary debates over community care in the late 1980s the issue of schizophrenia sufferers requiring different services from those with other mental illnesses was raised. In a House of Commons debate on community care on 12th June 1989 Clarke said 'schizophrenia is a particularly worrying condition; hospital treatment is absolutely necessary for all those suffering from acute schizophrenia'.<sup>98</sup> Another factor contributing to Parliamentary concern over schizophrenia was the issue of risk, with concern mounting from the 1980s onwards about the violent schizophrenics.<sup>99</sup> In 1986 the controversial organisation, SANE (Schizophrenia A National Emergency) was formed by journalist Marjorie Wallace following the publication of a series of articles written by her in *The Times* entitled 'Schizophrenia: The Forgotten Illness'.<sup>100</sup> Wallace, and SANE, aimed to reduce the stigma attached to schizophrenia, but criticism mounted that the organisation was

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<sup>97</sup> WL, PP/DSI/C/1/14, *Cart Before the Horse?*

<sup>98</sup> *Hansard's Parliamentary Debates*, 12 July 1989, vol. 156, cols 971-94.

<sup>99</sup> Elizabeth Walsh, Alec Buchanan, and Thomas Fahy, 'Violence and Schizophrenia: Examining the Evidence', *The British Journal of Psychiatry* (2002), pp. 490-95.

<sup>100</sup> Marjorie Wallace, 'The Forgotten Illness', *The Times*, 16 December 1985, p. 10.

actually contributing to this stigmatisation by highlighting the risk of having people with schizophrenia living in the community without adequate service provision. For instance, Wallace stated in *The Times* in 1985 that: 'Many families live in terror of their schizophrenic relative.'<sup>101</sup> Concerns that people with schizophrenia posed a threat to families and wider society were compounded in December 1992 when Jonathan Zito was stabbed to death by a paranoid schizophrenic, Christopher Clunis. In response, the media expressed panic and the Zito Trust was set up, recommending compulsory drug therapies for mental health patients who had at any time been violent.<sup>102</sup> However, whilst the NSF expressed concerns about whether people with schizophrenia would end up on the streets or in prison without adequate community provision, it was not as controversial as SANE or the Zito Trust and tended to focus primarily on the issue of informal carers at this time.

Carer organisations were broadly in support of the contents of the *Griffiths Report* and the *Caring for People* white paper. Indeed, *Caring for People* highlighted the need for carers to have respite care for the first time, an issue which carer groups, including Mencap, had long been campaigning for.<sup>103</sup> However, groups like Mencap were concerned that this rhetoric would not translate into action by the government. Whilst the *Griffiths Report* and *Caring for People* emphasised the role of relatives within mental health care and acknowledged that they required support to be able to adequately provide this care, these documents did not specify how this would be done nor were recommendations made for the establishment of

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<sup>101</sup> Ibid., p. 10.

<sup>102</sup> Nick Crossley, *Contesting Psychiatry: Social Movements in Mental Health* (London, 2006), pp. 191-201.

<sup>103</sup> WL, PP/DSI/A/3/1, AGM Minutes and Papers, 1979-2002, *AGM Minutes* (October 1982), pp. 2-3.

specific bodies or services to provide this role. Indeed, it was not until 1995, and the first Carers Act, that services were put in place specifically for carers.<sup>104</sup>

Following the *Griffiths Report*, Parliament began to draft what would become the NHS and Community Care Act. Carer groups were, on the whole, in support of the recommendations made by the *Griffiths Report*, particularly in terms of support for carers and the introduction of a Minister for Community Care.<sup>105</sup> However, a lack of clarity over the definition of community care, led interested parties to raise concerns over potential unexpected and unwelcome by-products and outcomes of community care policies. By 1989 the Conservative government seemed to have reached a clear understanding of what they understood by community care. Secretary of State for Health Kenneth Clarke set out in the opening to the House of Commons debate on Community Care on 12 July 1989 that 'Community care is a policy to which successive Governments have been committed for almost 30 years. The key aim of the policy is to enable people to live as full and independent a life as is possible for them to do in the community for so long as they wish to do so.'<sup>106</sup>

Conceding that discharged long-stay patients would have different requirements to those who had always lived in the community, Clarke's definition clearly played into the rights agenda of the decade and remained broad enough to spark debate. In the 1980s, service-user and disability rights campaigners lobbied for those with mental illnesses and learning disabilities to have equal opportunities

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<sup>104</sup> Jacqueline M. Atkinson and Denise A. Coia, 'Viewpoint: Carers, the Community and the White Paper', *Psychiatric Bulletin*, 15:12 (1991), p. 763.

<sup>105</sup> LSE Archives and Special Collections (LSEA), Morris, Alfred, MORRIS/1/15/5, Parliamentary Briefings, *Letter from Age Concern* (September 1989), p. 4, WL, PP/DSI/C/1/4, *Mental Hospital Closures: What the run-down means to people with schizophrenia. And to you*, p. 7.

<sup>106</sup> *Hansard's Parliamentary Debates*, 12 July 1989, vol. 156, cols 971-94.

and agency over their own lives and treatment.<sup>107</sup> Clarke's definition itself contained ambiguities, not least in terms of the place of the carer within community care. NSF medical advisor John Wing was concerned that for service-users 'to live as full and independent a life as is possible' there would a cost in terms of carers' independence and quality of life. As early as 1971 he had asserted that schizophrenia placed 'a considerable burden . . . on the health, leisure, and finances of families'.<sup>108</sup> It could be assumed that providing mental health care services would negate the need to provide services for their relatives. However, the NSF was concerned that community-based services would not be forthcoming, a concern which created tension between the NSF and service-user group MIND. Contrary to the NSF, MIND was broadly in favour of the swift closure of long-stay institutions. MIND's civil libertarian stance meant that it supported patients' rights above those of their familial carers.<sup>109</sup>

Care *by* the community was not an entirely novel consequence of community care policies. Carer organisations were therefore able to draw upon a wealth of prior knowledge and experience of its members struggling to care for relatives with a mental disorder to argue the case against placing the burden of care on relatives with little or no additional support. To demonstrate that poorly

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<sup>107</sup> This was part of a broader human rights movement at the time. See, Virginia Berridge, 'Case Study: Sexual Health', in Martin Gorsky, and Alex Mold (eds), *Public Health in History* (Maidenhead, 2011), p. 105; Gareth Millward, 'Invalid Definitions, Invalid Responses: Disability and the Welfare State, 1965-1995' (PhD Thesis, London School of Hygiene and Tropical Medicine, 2013).

<sup>108</sup> John Wing, 'How Many Psychiatric Beds?', *Psychological Medicine*, 1:3 (1971), p. 189; This point is reiterated in Lucy Johnstone, *Users and Abusers: A Critical Look at Traditional Psychiatric Practice* (London, 1989), p. 83: 'family life, household routines, social and leisure activities are all severely disrupted'.

<sup>109</sup> WL, PP/DSI/B/3, Miscellaneous Consultation Documents, 1977-1991, *Comments on DHSS Review*, p. 6; WL, PP/DSI/C/4/2, National Schizophrenia Fellowship Newsletter, NSF News, 1980-1986, *NSF News* (April 1986), p. 2; Peter Sedgwick, *Psycho Politics: Laing, Foucault, Goffman, Szasz, and the Future of Mass Psychiatry* (London, 1982), p. 215, p. 242.



enacted community care policies could have unwelcome implications for carers, carer organisations highlighted the long history of familial care for mental illness and mental handicap, departing from traditional historical accounts of community care. Carer organisations, and indeed other interested parties, lobbied interested members of parliament. In a briefing to shadow Minister for the Disabled, Alf Morris, in 1989/90 Mary Holland, MENCAP's parliamentary assistant, explained:

One of the myths of care in the community is that the majority of people with mental handicap are now moving out of long-stay hospitals into the community. The fact is that the majority of people with mental handicap have always lived in the community with their families.<sup>110</sup>

Holland is suggesting that by acknowledging the long history of care in the community, politicians would be better equipped to realise that families required additional support from the state. Holland informed Morris that 'families are the backbone of community care policies, but if they are to continue to provide this care, they need to have support across the board.'<sup>111</sup> In the briefing Holland also included an account from a parent imploring the government to consider the experiences of families in future legislation:

In the case of a handicapped child, the whole responsibility mustn't be laid with the parents. And if there's any hardship at all, for any part of the family's work - earnings, spending or whatever - the Government should help with it. . . I think the

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<sup>110</sup> LSEA, MORRIS/1/15/4, Disability, Community Care, 'Briefing from Mary Holland at MENCAP for debate on disability 24 January 1990', (19 January 1990), p.1.

<sup>111</sup> LSEA, MORRIS/1/15/4, 'Mary Holland', p.1.

Government should consider the effect on all members of the family. Not just the husband. Probably he's in the best position of all, because he can leave the four walls, whereas the wife and other children can't. There should be some money to compensate the other children, the other members of the family - compensation for stress or the environmental effects.<sup>112</sup>

Carer organisations had long been keen to establish a dialogue with Parliament, a link that they capitalised on during the readings of the NHS and Community Care Bill. For instance, the NSF's parliamentary officer Dorothy Silberston lobbied both Houses of Parliament and was represented on parliamentary health committees, thus establishing a role in mental health policy making. Historians Matthew Hilton James McKay, Nicholas Crowson and Jean-Francois Mouhot, have argued that this was not uncommon among groups, like the NSF, who had 'long-established connections with the civil service, bestowing an aura of credibility which more recent (and perhaps more radical) groups of disabled people have not easily emulated.'<sup>113</sup>

Certain politicians, including Morris, were particularly sympathetic to the issue of family carers. Carer lobby groups concentrated their efforts on these politicians, and this led to the issue of the family carer being raised in parliamentary debates, particularly those in the run up to the passing of the NHS and Community Care Bill. The debates that took place during the formulation of the NHS and Community Care Act were not exclusively focused on carers, let alone carers for mental illness and learning disability. Carer organisations therefore had to work

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<sup>112</sup> LSEA, MORRIS/1/15/4, 'Mary Holland', p. 2.

<sup>113</sup> Matthew Hilton, James McKay, Nicholas Crowson and Jean-François Mouhot, *The Politics of Expertise: How NGOs Shaped Modern Britain* (Oxford, 2013), p. 134.

hard to ensure that informal carers for mental illness and mental handicap remained on the social policy agenda. Labour MP Jack Ashley helped to raise the profile of carers when he passionately argued in 1989 that:

Devoted family carers are the kingpins of community care, but despite the bromides there are no specific proposals to help them - merely a mention in a white paper . . . The Bill fails to recognise the army of carers who are being exploited and overstretched, many of whom are themselves very frail.<sup>114</sup>

A particular concern for Labour politicians was a service gap resulting from hospital closures and inadequate service provision. For instance, Alf Morris argued:

How does the Secretary of State square what he said about appropriate care for the mentally ill with the closure this Friday of a 24-bed hospital ward for the mentally ill in south Manchester, which in the words of their consultant, means that his patients will have to wander the streets with nothing to do and nowhere to go?<sup>115</sup>

In this statement Morris casts light on the contradiction between hospital closures and the reluctance, or inability, of some relatives to provide care. Rather than continuing the rhetoric which assumed that relatives would fill the gap in community care service provision, Morris' statement shows an awareness of the

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<sup>114</sup> *Hansard's Parliamentary Debates*, 7 December 1989, vol. 163, cols 488-569.

<sup>115</sup> *Hansard's Parliamentary Debates*, 12 July 1989, vol. 156, cols 971-94.

carers' lobby position that not all relatives were in a position to fill the care gap following the discharge of long-stay patients.

Despite the viewpoints of supporters of carers for mental illness and mental handicap being discernible in political discourse during the 1980s, there were also challenges to this standpoint. As has already been mentioned, the interests of the carer lobby were often at odds with the service-user movement. Cost implications and right-wing think tanks also presented a challenge. Thatcherism marked a move away from public-funded services in favour of the neo-liberal model of a small state with a free market, with a focus on the individual rather than the community.<sup>116</sup> Added to this was a decline in political influence of left-wing advisors which had held sway in the 1970s. As Bagguley has argued, a lack of Labour governance from 1979 led to a marginalisation of groups like the Child Poverty Action Group.<sup>117</sup> Instead, the right-wing think tank the Centre for Policy Studies, created in 1974 by Sir Keith Joseph and Margaret Thatcher, became increasingly influential. This shift made the state-provision of community-based services less likely. However, it is important to note that government funding of carer and service-user groups actually increased during the 1980s. It could be argued that this spending ensured that services run by these groups in the community were in actual fact funded, at least in part, by the state.<sup>118</sup>

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<sup>116</sup> Stuart Hall, 'The Neo-Liberal Revolution', *Cultural Studies*, 25:6 (2011), pp. 705-28; Ben Jackson, 'The Think Tank Archipelago: Thatcherism and Neo-Liberalism', in Ben Jackson and Robert Saunders (eds), *Making Thatcher's Britain* (Cambridge, 2012), pp. 43-61.

<sup>117</sup> Bagguley, 'Collective Action', pp. 40-41.

<sup>118</sup> Mathew Hilton, James McKay, Nicholas Crowson and Jean François Mouhot, "'The Big Society': Civic Participation and the State in Modern Britain', *History and Policy*, June 2010. <<http://historyandpolicy.org/papers/policy-paper-103.htm>> (17 April 2012), pp. 1-8. As a counter-point, sociologist Andrew Scull has argued that the state cut funding during the deinstitutionalisation process: Andrew Scull, 'Deinstitutionalization and Public Policy', *Social Science and Medicine*, 20:5 (1985), pp. 550-51.

Despite the issue of familial care in mental health care being more commonly acknowledged and discussed by the end of the 1980s, the NHS and Community Care Act did not address concerns over the well-being of carers. The Act gave those who needed community services the right to an assessment by their local authority to help them access appropriate services. However, this right to assessment was only extended to carers for mental illness and learning disability in the 1995 Carer (Recognition and Services) Act. It seems likely that another factor contributing to the NHS and Community Care Act's failure to establish services for carers was the tension between some caring relatives not wanting to be perceived as carers or in receipt of help from professionals and other carers, including a majority of NSF members, who did not want to provide care for their relatives. Indeed, it was the hope of some carers and carer organisations that community care legislation would remove 'the burden of care' from relatives with the provision of community-based, residential, services for those with severe mental illnesses and learning disabilities.

In summary, during the 1980s carer groups, including the NSF, and other interested parties attempted to negotiate the category of the carer as it became increasingly codified in social policy documents. Rather than antagonising policy makers, carer groups worked within the system exploiting channels of communication established during the 1970s in the form of parliamentary officers.<sup>119</sup> Many carers, in line with carer organisations, felt an entitlement to service provision and wanted a say in the way community care legislation was

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<sup>119</sup> Gareth Millward, 'Social Security Policy and the Early Disability Movement: Expertise, Disability, and the Government, 1965-77', *Twentieth Century British History* (Advanced Access, October 2014), pp. 1-24.

formulated whilst also being resistant to the state's expectation that families should be the main providers of community care. Carer groups for mental illness and learning disability stressed the need for specialist residential care, especially during phases of acute illness. In this respect, schizophrenia was frequently discussed in parliamentary debates on community care as the condition was both acute and chronic, and relatives often struggled to care for those with the condition at home. As such, mental illness and mental handicap were often discussed separately from other forms of chronic illness in debates around informal care. Although there was a dialogue between carer groups and politicians, their influence was often limited due to cost implications and the impact of right-wing think tanks, which became growing concerns during the 1980s.

### **Carers Enacted, c.1995-1999**

Between 1995 and 2004 three successive Carers Acts formally acknowledged the role of unpaid carers and began to put requirements in place for local authorities to assess carers' ability to provide care.<sup>120</sup> This section focuses on the 1995 Carers (Recognition and Services) Act and the 1999 *Caring about Carers: National Strategy for Carers*.<sup>121</sup> Several factors lay behind the legislation. These documents were the culmination of decades of research into carers' needs with evidence being gathered, discussed, and disseminated by social scientists, medical professionals,

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<sup>120</sup> For an examination of the Carers Acts of 2000 and 2004 see the Epilogue in the Conclusion of this Thesis.

<sup>121</sup> *Carers (Recognition and Services) Act*; Department of Health, *Caring about Carers*.

and carer organisations. Calls for greater recognition of carers' needs came from these groups, but also second-wave feminists and politicians. A 1995 publication by disability charity SCOPE stated: 'despite the fact that informal carers save the country £30 billion a year by giving their time free of charge, carers are not adequately recompensed and many experience hardship.'<sup>122</sup> The Department for Health and Social Security initiated General Household Survey (GHS) studies of informal carers in 1985, 1990, and 1995, which directly informed the 1995 Carers Act.<sup>123</sup> Finally, a political focus on rights in the 1980s and 1990s created a discourse in which carers' entitlement in terms of both access to state health care provision, and also to a degree of agency and choice over this health care provision, spurred on the formation of this legislation.

However, even after the carer had become an official category the role continued to be negotiated and whilst some believed the legislation had gone too far, others felt it had not gone far enough. Indeed, this legislation required those relatives that could provide care to assume the responsibility to do so. By the mid-1990s carers for mental illnesses and learning disabilities were considered part of the broad category 'carer'. This was a significant development in the emergence of the family carer for mental illness and learning disability, because much of the social policy related to caring throughout the post-war years had been initiated by, and preoccupied with, concerns over an ageing population.

Carers were given a clear legal status for the first time in 1995 when the first Carers Act formally recognised the role of unpaid carers. This legislation did not

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<sup>122</sup> Brian Lamb and Sarah Layzell, *Disabled in Britain: Behind Closed Doors. The Carers' Experience* (London, 1995), p. 51.

<sup>123</sup> A more detailed analysis of the General Household Survey studies into Informal Care can be found in Chapter Two of this thesis.

directly refer to carers for mental illness and learning disability, but this group of carers were included within the remit of the Act. The Act was the result of a successful private member's bill by Labour MP Malcolm Wicks which was adopted by John Major's Conservative government. Malcolm Wicks had read sociology at LSE, becoming the director of the Family Policy Studies Centre in 1983. Wicks had a particular interest in the issue of poverty, particularly among the elderly.<sup>124</sup> Wicks' first speech to Parliament included an account of an encounter he had with an elderly homeless man who had been discharged into the care of the community following thirty-five years in a mental hospital. Wicks' 1978 book, *Old and Cold*, discussed the issue of fuel bills and he later became vice-president of Carers UK and the Alzheimer's Society.<sup>125</sup>

The 1995 Act entitled carers to request an assessment from their local authority of their ability to provide, and to continue to provide, care. During these assessments carers could tell social services what would make the caring role easier for them. Although carers were unrestricted by age, they could only request an assessment when the person they were caring for was having an assessment or reassessment.<sup>126</sup>

Although this legislation began to perceive carers as having needs distinct from those with disabilities who they cared for, the two categories were closely related by the Act. The Carers Assessment was required to be taken into account by local authorities when planning which community care services were going to be made available to the person in need of care. Throughout the 1990s and early

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<sup>124</sup> Julia Langdon, 'Malcolm Wicks Obituary', *Guardian*, 30 September 2012.

<sup>125</sup> Malcolm Wicks, *Old and Cold: Hypothermia and Social Policy* (London, 1978).

<sup>126</sup> *Carers (Recognition and Services) Act*, pp. 1-4.



2000s a key issue of debate was whether support should be directed at disabled people or their carers, a debate which had previously manifested in the tension between service-user and carer groups.<sup>127</sup>

In relation to the work of economist and social policy academic Julian Le Grand, this legislation was formed as part of a social welfare model which was based not on the universal entitlement to welfare by passive recipients as the welfare state had once been, but instead as a system based on incentives with financiers, operators, and users behaving in line with self-interest.<sup>128</sup> Le Grand acknowledged that 'in order to provide an adequate level of finance for [long-term, community-based,] care, it will have to rely in part on private resources, both in financial terms and in terms of time and effort provided by informal carers.' He also noted that to be effective this would need to both generate enough resources and 'not seem punitive in implementation'.<sup>129</sup> Although not providing as robust a policy as Le Grand envisaged, the subsequent Carers Act did attempt to bestow upon carers rights and concessions as well as responsibilities.

Feminist sociologists Janet Finch and Jennifer Mason were concerned by attempts by Conservative governments in the 1980s and early 1990s to 're-draw the boundary between state responsibilities and family responsibilities to place more in the realm of the family.'<sup>130</sup> In 1993 they wrote that 'people *do* accept responsibilities to help relatives, sometimes at considerable cost to themselves. But

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<sup>127</sup> Hilary Arksey and Caroline Glendinning, 'Informal Welfare', in Pete Alcock, Margaret May and Sharon Wright (eds), *The Student Companion to Social Policy* (4th edn, Chichester and Hoboken, 2012), pp. 237-38.

<sup>128</sup> Le Grand, 'Knights', p. 160. See also, Rodney Lowe, *The Welfare State in Britain since 1945* (2nd edn, Basingstoke, 1995).

<sup>129</sup> Le Grand, 'Knights', p. 164. Le Grand goes into more detail about Partnership schemes for long-term care here: Julian Le Grand, *Motivation, Agency, and Public Policy: Of Knights & Knaves, Pawns & Queens* (Oxford, 2006), pp. 141-46.

<sup>130</sup> Finch and Mason, *Negotiating*, p. 177.

we all, it would seem, want to retain the right ultimately to say that we do it of our own choosing'.<sup>131</sup> The rhetoric used by successive governments was one of prescriptive assumption that families should provide care for their relatives.<sup>132</sup> In a similar vein a 1995 publication by SCOPE stated that:

Few unpaid carers choose to become the carer of a disabled person; it is a role they take on because it is expected of them and there is no-one else to do it. . . Once they are faced with a situation in which care is required, most people feel that it is not "right" to use institutional care, except as a last resort. However, when they begin caring, few people are aware of the extent to which their lives will be affected.<sup>133</sup>

By formally recognising the vital role played by carers the 1995 Act reinforced the obligation and duty felt by many relatives. Indeed, it could be argued that much of this feeling of obligation was, as Finch and Mason have suggested, the result of government rhetoric.

Carer groups, medical professionals, and researchers had argued since the 1970s in favour of respite care for familial carers of mental illness and mental handicap. In 1999 the National Strategy for Carers established a Carers Special Grant of £140 million over a three-year period for local authorities to develop flexible and innovative services so that familial carers could take a break. The publication, entitled *Caring about Carers*, began with a foreword from Prime Minister Tony Blair which stated: 'caring for carers is a vital element in caring for

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<sup>131</sup> Ibid., p. 180.

<sup>132</sup> Finch, *Family*, p. 237; Finch and Mason, *Negotiating*, p. 166.

<sup>133</sup> Lamb and Layzell, *Disabled*, p. 2.

those who need care.' Rather than replacing carers with state-run services, Blair pledged that 'what carers do should be properly recognised, and properly supported'.<sup>134</sup> *Caring about Carers* included information drawn from the 1995 GHS and examples of good practice from charitable bodies, including the NSF. The strategy was based on the ethos that anyone could become a carer or be in need of a carer. The hope was that by providing information, support, and care, caring would become 'something that people can do with pride.' The document called for 'all organisations involved with caring' to begin to focus on the carer as opposed to just the client, patient or user.<sup>135</sup> In accordance with social scientific research from the 1970s, the well-being of carers was highlighted as a cause for concern, including the prevalence of mental health issues amongst carers. One of the report's conclusions stated: 'we need to achieve a cultural change in the way society as a whole . . . perceive caring. Carers should not be pitied, but respected and admired.'<sup>136</sup> The report therefore did not perceive improvements to carers' lives and well-being as being the full responsibility of the state, but hoped for carers and broader society to reconceptualise caring as a positive and vital role. By the end of the 1990s the state was beginning to acknowledge that carers had their own individual needs that could be unrelated to the condition or disability of their dependent. The state was slow to make improvements to carers' lives, but carers were starting to be considered less as resources and more as active citizens within, or consumers of, social welfare. The National Strategy employed a rhetoric of individuality and individual needs when referring to family carers. New Labour

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<sup>134</sup> DH, *Caring about Carers*, pp. 3-4.

<sup>135</sup> *Ibid.*, pp. 5-6.

<sup>136</sup> *Ibid.*, p. 83.

perceived carers to be individuals with rights, in addition to having responsibilities to their families.<sup>137</sup> Whilst the New Labour publication *Caring about Carers* marked a new government commitment to legislate for the needs of carers, it was similar in tone to the rhetoric of individualism and family responsibility usually associated with Thatcherism.<sup>138</sup>

In conclusion, this section has examined the 1995 Carers Act and the National Strategy for Carers (1999) to demonstrate that by the 1990s carers were conceived in legislation as having needs and rights distinct from, but closely related to, those with mental illnesses and learning disabilities. Assessments were introduced to ascertain to what extent informal carers could provide care for their relatives and carer specific services and respite care were established. Whilst this legislation was very much focused on the broad category of the carer, including carers for the elderly, the sick, and the disabled, carers within the mental health sphere were also included. These measures built upon research conducted in the 1970s and 1980s which found that carers needed support beyond simply financial assistance and were in line with calls from carer groups to better support those caring for relatives. Carers, like other welfare users, felt an entitlement for their relatives to be able to access welfare services if they wished. In addition, many carers wanted to be able to give over the responsibility of care for their relative to the state if they felt unable, or unwilling, to cope. Thus, these policy documents followed a series of proclamations that relatives were the main providers of

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<sup>137</sup> Marian Barnes, 'Welfare Users and Social Policy', in Pete Alcock, Margaret May and Sharon Wright (eds), *The Student Companion to Social Policy* (4th edn, Chichester and Hoboken, 2012), pp. 280-81; Catherine Bochel, 'State Welfare' in Pete Alcock, Margaret May and Sharon Wright (eds), *The Student Companion to Social Policy* (4th edn, Chichester and Hoboken, 2012), p. 213.

<sup>138</sup> Hall, 'Neo-Liberal', pp. 705-28.

community care but also marked an acknowledgement that not all relatives were able to provide care. This demonstrates that the viewpoints of those campaigning for family care-givers, who wanted them to have a choice over whether they became carers, whilst also being recognised as experts, were beginning to be incorporated into social policy. However, the carer role was still being negotiated with some arguing legislation had not done enough, and others asserting that it had gone too far, advancing the wishes of carers at the cost of disability rights.

## **Conclusions**

This chapter has taken a fresh approach to the study of the history of community care, considering not just the reality of legislative changes and the implication, or lack thereof, of community-based services, but also considering ideological perceptions of community care. As a slow and long-term process with a largely empty label, community care provided a flexible framework in which interested parties could attempt to advance their own visions of the future of mental health care, and care more broadly, and the place of the informal carer within it. Ironically, as community care legislation was reassessed in the 1970s and 1980s culminating in the NHS and Community Care Act (1990), there was considerable acknowledgement of the uncertainty of what community care actually meant. Here, I have argued that the uncertainty over both the reality of and visions for community care offered a space in which the place of the carer in mental health care and in broader community care was debated and negotiated.

In terms of social welfare, the decades between the 1959 Mental Health Act and the 1999 National Strategy for Carers were dominated by a policy of community care. However, throughout this period there was considerable uncertainty and debate across the board about what community care did or could mean. For carers for mental illness and mental handicap, this debate was configured around the issue of who should, could, or would provide care. Throughout the period, carers remained on the social policy agenda. Three factors were particularly important in this: firstly, the relationship between the problem of care for those with mental illnesses and learning disabilities and the related concerns about an ageing population; secondly, the shifting place of women within the post-war family and wider society; and thirdly, calls for entitlement to state provided social care.

Families had cared for mentally ill and mentally handicapped relatives in the home for centuries but it is well documented that these families could, and did, turn to institutional care during times when they were unable to manage their ill relative at home, especially during the nineteenth century. However, the policies of deinstitutionalisation and community care not only threatened to destabilise this arrangement, but also aroused fears that the familial role in care would not only be expected, but could be prescribed by the state. In the context of widespread feeling that British citizens had an entitlement to state welfare provision and with a growing interest in, and awareness of, the day to day experiences and hardships of family carers, carers and those campaigning on behalf of carers, attempted to renegotiate the place of the carer in mental health care. Whilst wanting to resist the burden of care, these campaigners also wanted relatives to be seen as experts

and to have a degree of agency and choice over their role in the care of their relative. At the same time, other groups including second-wave feminists became interested in the issue of care and spurred on these debates giving them a wider platform.

Between the early 1960s and the close of the twentieth century family carers therefore began to be referred to as one of the main providers of community care and this increasing recognition led to the implementation of benefits for carers, services specifically for carers, and assessments to ascertain the ability of carers to provide care. At the same time the carer became an identity which people could self-identify with or have ascribed to them. Yet, some people who identified themselves as carers found that they were not able to claim state benefits, for example because they did not fit within the definition of a carer provided by social policy documentation. By the end of the 1990s, the definition of family carer was beginning to be nuanced by the state, with a recognition that carers were individuals with their own needs, that could not be wholly defined by the condition or disability of the relative they were caring for

## 2.

### **The Identification of the Family Carer as a Subject of Social Research, c. 1956-1998**

In this chapter I argue that social researchers, from a range of disciplines, played a key role in the emergence and subsequent development and negotiation of the role of the family carer in post-war mental health care in England and Wales. Building upon experiences during the Second World War, sociological methodologies were perceived by governments and those within the medical profession to offer tools that could adeptly 'measur[e] the characteristics of people'.<sup>1</sup> During the Second World War governments became interested in using the social survey to better understand the health of the population.<sup>2</sup> Given the growing interest in the psychosocial at the time, this also allowed researchers to develop new understandings of the role of social groupings and environment on health. In the context of the growing authority of social science in the post-war period, a new

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<sup>1</sup> David Armstrong, 'Medical Sociology', in W.F. Bynum and Roy Porter (eds), *Companion Encyclopaedia of the History of Medicine* (London and New York, 1993), p. 1643. See also: Nikolas Rose, 'Psychology as a Social Science', *Subjectivity*, 25:1 (2008), p. 452-53; Mathew Thomson, *The Problem of Mental Deficiency: Eugenics, Democracy and Social Policy in Britain c. 1870-1959* (Oxford, 1998), p. 241-4.

<sup>2</sup> Rhodri Hayward, *The Transformation of the Psyche in British Primary Care 1880-1970* (London, 2014); pp. 79-80.



generation of social researchers became interested in the study of the community in the 1950s, 1960s, and 1970s.<sup>3</sup> At this time, the concepts of family, care, mental illness, mental handicap, and indeed community were uncertain, with social policy related to these phenomena in flux, creating a range of subject matter for social researchers to investigate. Some of these researchers, including social psychiatrists, sociologists, and ethnographers, began to locate a hitherto largely hidden world of mental illness and mental handicap within the family. In doing so they illuminated, constructed, and problematised the family carer. The extent of this unveiling is evident from the inclusion of a section on 'informal carers' in the Office of National Statistics' (ONS) General Household Survey (GHS) for the first time in 1985.<sup>4</sup> This inclusion indicates that the role of the carer was considered to be widespread enough in England and Wales at the time to generate meaningful statistics from a sample survey and that the government were generating data on informal carers to inform social policy change.

Whilst historians have tended to overlook the role of the family in mental health care in the post-war period, there has been more recent interest in the history of the rise of social science during the same period.<sup>5</sup> This chapter demonstrates that the two histories are in many respects intertwined. Social science gained authority during, and following, the Second World War as governments became interested not only in assessing the state of their nations, but

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<sup>3</sup> David Armstrong, *Political Anatomy of the Body: Medical Knowledge in Britain in the Twentieth Century* (Cambridge, 1983), pp. 98-100; Mike Savage, *Identities and Social Change in Britain since 1940: The Politics of Method* (Oxford, 2010), pp. 203-11, pp. 112-164.

<sup>4</sup> Hazel Green, *Informal Carers: A Study carried out on behalf of the Department of Health and Social Security as part of the 1985 General Household Survey* (London, 1988), p. 4.

<sup>5</sup> For comment on the under-researched topic of the family and mental health care, see: Thomson, *Mental Deficiency*, p. 2; David W. Jones, 'Madness, the Family and Psychiatry', *Critical Social Policy*, 22 (2002), p. 247. For a recent work on the development of social science in the post-war period, see: Savage, *Identities*.

also in adopting tools to better govern their populations, including the sample survey.<sup>6</sup> As early as 1985, an edited volume by sociologist Martin Bulmer indicated that social researchers themselves were actively aware of the relationship between research and social change.<sup>7</sup> In this volume, fellow sociologist Peter Townsend argued that the social survey could 'be used imaginatively to reveal . . . the complexities of political and social policies.'<sup>8</sup>

More recently sociologist Mike Savage has offered a more nuanced analysis of the place of the sample survey in post-war society, arguing that:

the sample survey proved a mechanism by which the characteristics of even obscure social groups could be delineated through defining their aggregate characteristics. . . [until] the later 1960s, it remained more common to conduct a sample survey on a specific group, often in a particular location, than on a national random sample, . . . we can therefore see the survey as being an important device for eliciting social categories into meaningful ones.<sup>9</sup>

In this way, social scientific research could be said to create and shape phenomena, not least because social science research shared a reciprocal relationship with social policy change.<sup>10</sup> At the same time, psychological thinking became more prominent and influential. Some researchers began to marry psychological and sociological

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<sup>6</sup> Rose, 'Psychology', p. 454; Savage, *Identities*, pp. 188-89

<sup>7</sup> Martin Bulmer (ed.), *Essays on the History of British Social Research* (Cambridge, 1985).

<sup>8</sup> Peter Townsend, 'Surveys of Poverty to Promote Democracy', in Martin Bulmer (ed.), *Essays on the History of British Social Research* (Cambridge, 1985), p. 234.

<sup>9</sup> Savage, *Identities*, p. 190, pp. 195-96, p. 201, p. 204.

<sup>10</sup> Matthew Smith has made this argument for the American context: Matthew Smith, 'Psychiatry Limited: Hyperactivity and the Evolution of American Psychiatry, 1957-1980', *Social History of Medicine*, 21:3 (2008), pp. 454-455. See also: J.K. Wing, 'Social Psychiatry', in Paul E. Bebbington (ed.), *Social Psychiatry: Theory, Methodology, and Practice* (New Brunswick, 1991), p. 19.

methodologies together to consider various phenomena in light of the psychosocial.<sup>11</sup>

This chapter focuses on the reasons why social researchers became interested in the role of the carer in mental health care, the ways in which this research was explored and developed throughout the period, and the consequences of the emergence of the family carer as a subject of social research. Firstly, I introduce some of the ways in which family care-giving came to be identified as a subject of social science research from the 1960s onwards and the implications of these explorations. Specific reference will be made to Enid Mills' *Mental Illness and the Family* (1962) and Sheila Hewett's *The Family and the Handicapped Child* (1970). Secondly, I turn to focus on the particularly illuminating case study of the Medical Research Council's (MRC) Social Psychiatry Unit (SPU). Social psychiatry, a trajectory of psychiatric research, utilised social scientific methods as part of its distinctively interdisciplinary approach. Along with the links between social psychiatry and social policy, the work of the SPU, particularly its research on 'expressed emotion', can help us to understand why and how the family carer came to be recognised as an issue. Thirdly, I consider the inclusion of questions on informal care in the General Household Surveys of 1985, 1990, and 1995, along with the body of sociological work on informal care which succeeded

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<sup>11</sup> For a history of the psychosocial, see: Rhodri Hayward, 'Enduring Emotions: James L. Halliday and the Invention of the Psychosocial', *Isis*, 100:4 (December 2009), pp. 827-38; Rhodri Hayward, 'The Invention of the Psychosocial: An Introduction', *History of the Human Sciences*, 25:3 (2012), pp. 3-12. For the role of psychiatry, and the psychiatric gaze, in post-war Britain, see: David Armstrong, *The Political Anatomy of the Body: Medical Knowledge in Britain in the Twentieth Century* (Cambridge, 1983); Nikolas Rose, *Governing the Soul: The Shaping of the Private Self* (London, 1989); Mathew Thomson, *Psychological Subjects: Identity, Culture, and Health in Twentieth-Century Britain* (Oxford, 2006).

these reports. As all of these surveys considered class and gender differentials in their analyses I will include these themes in this chapter.

Ultimately, I argue that growing interest and confidence in post-war social science became fused with an emerging discourse around both social and mental health care policy change from the late 1950s onwards. As a result, the family carer was identified as a subject of social enquiry. Subsequently, in line with sociologists David Armstrong and Mike Savage's theses, these researchers created and shaped the carer as a phenomenon in social policy, as well as in public and media discourse, whilst also changing the identities of the carers themselves. Social researchers thus contributed to contemporary discourse on the place of the carer in mental health care and facilitated the politicisation of the carer as an issue which required further study and debate. This in turn relates to philosopher Ian Hacking's work on the production of particular types of people – in this case, carers.<sup>12</sup> By the 1980s carers had been transformed from a novel, vague, and semantically underdeveloped subject of social scientific research into an increasingly distinctive group of actors. This move was facilitated by social scientists. By the 1990s family carers for mental illness and learning disability were considered within a broader category that also encompassed care for the elderly and people with physical disabilities. Social researchers, driven in part by the needs of policy makers, began to categorise family carers more in terms of the hours of time spent caring and the nature of caring activities, rather than the condition, illness, or disability of the care recipient.

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<sup>12</sup> Ian Hacking, 'Making Up People', in Mario Biagioli (ed.), *The Science Studies Reader* (London and New York, 1999), pp. 161-71. For further consideration of these ideas, see Ian Hacking, *The Social Construction of What?* (Cambridge, 1999).

## Home-based Family Interviews, c. 1956-1970

As explained in the Introduction and in Chapter One of this thesis, from the 1960s onwards the government adopted a policy of community care and the deinstitutionalisation of long-stay mental hospital patients. This provided social scientists with an opportunity to investigate the experiences of families with a mentally ill or mentally handicapped relative. The study of the phenomenon of familial care was driven by a variety of forces, including the expanding field of community studies research, financial support from non-governmental organisations (NGOs) or government departments, new research methodologies, proposed changes to social policy, and a desire to build upon existing surveys. These factors, along with a preoccupation with sociological explorations of the nature of community, mental illness, mental handicap and the family, brought social scientists into the homes of families. In relation to the mental health field, researchers became interested in the nature, and effectiveness, of community care, and in particular care *by* the family. These researchers subsequently gained new insights into the role of family members in care, and thus contributed to the emergent category of the carer. As Savage has explained: ‘survey methods were used to trace individuals over time so that their changes could be analysed and appropriated into an understanding of the “developmental individual”’.<sup>13</sup> In this section I examine two pieces of social scientific research in detail, one on the relationship between the family and mental illness and the other on mental handicap.

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<sup>13</sup> Savage, *Identities*, p. 204, p. 205, p. 210.

One of the earliest of these studies was sociologist Enid Mills' *Living with Mental Illness* (1962). Mills' study was part of the broader Institute of Community Studies (ICS) which was founded in 1953 by sociologist Michael Young and began work in 1954, when Peter Townsend and Peter Willmott joined the Institute. The jacket sleeve of *Living with Mental Illness* stated the Institute's mission statement:

the Institute has tried to bring some of the strengths of anthropology to sociology, combining personal observation and illustration with statistical analysis. The aim is to undertake research which will both add to basic knowledge about society and illuminate practical questions of social policy, and to publish the findings in a form which will interest the layman as well as the specialist.<sup>14</sup>

The ICS's research on the theme of community utilised innovative social science methodologies, combining anthropological and sociological methods to explore social networks and in an attempt to delimit working-class identities. Peter Willmott explained that this novel methodological approach was made possible because the ICS was independent of any university or institution. This also enabled the ICS to research diverse topics related to the themes of community and social networks. However, some sociologists saw the ICS as a threat to sociology as a 'specialised body of knowledge', and although the ICS's qualitative approach had been used by other research groups, including Mass Observation, some dismissed the Institute's publications as journalistic.<sup>15</sup>

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<sup>14</sup> Enid Mills, *Living with Mental Illness: A Study in East London* (London, 1962).

<sup>15</sup> James Hinton, *The Mass Observers: A History, 1937-1949* (Oxford, 2013), p. 372; Willmott, 'The Institute', pp. 137-50. See also: Savage, *Identities*, p. 195, p. 216.

The ICS hoped to influence social policy by informing policy makers on the needs of working-class people, by conducting research around an array of themes including old age, social change, and education. These studies, which focused on the themes of family and community, tended to be conducted in the predominantly working-class London borough of Bethnal Green.<sup>16</sup> This location was selected for a number of reasons, among them that Young had already conducted research there in 1951, and the area was compact with a predominantly working-class population of which many had been re-housed.<sup>17</sup> The ICS was primarily concerned with the potential impacts of community breakdown on issues including the support of extended families and family care-giving. The ICS quickly realised that it was more likely to have a policy-impact if it focused more on longer-term policy objectives, rather than detailed, shorter-term policy recommendations.<sup>18</sup>

Significantly, the ICS began researching communities and developing a community studies' methodology at a similar time to moves towards community care. The nature and shortfalls of community care were therefore being discussed at the same time as the 'community' was being expected to provide welfare provision the state was no longer willing to provide, for instance via mental hospitals. Whilst uncertainties over the 'community' component of community care continued into the 1980s, the ICS was no longer conducting community studies by this time. This was, to a large degree, because of its lack of ability to win funding

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<sup>16</sup> Other studies by the Institute of Community Studies included: Brian Jackson and Dennis Marsden, *Education and the Working Class: Some General Themes Raised by a Study of 88 Working-Class Children* (London, 1962); Peter Townsend, *The Family Life of Old People: An Inquiry in East London* (London, 1957); Peter Willmott and Michael Young, *Family and Class in a London Suburb* (London, 1960).

<sup>17</sup> Peter Willmott, 'The Institute of Community Studies', in Martin Bulmer (ed.), *Essays on the History of British Sociological Research* (Cambridge, 1985), pp. 137-50.

<sup>18</sup> *Ibid.*, pp. 142-43.

once social research units became established in university departments. However, Willmott has argued that this was not because community no longer merited study, as by the 1980s there was a 'greater diversity of life-styles and the upsurge of community action.'<sup>19</sup>

Mills joined the ICS in 1957 following the completion of a degree in sociology from the prestigious social science training ground, the London School of Economics and Political Science (LSE). By 1961 Mills was working as a sociologist at the Psychiatric Rehabilitation Unit at Woodberry Down Health Centre in London. Published in 1962, the research for Mills' study was undertaken between 1958 and 1959, shortly after the Royal Commission on the Law Relating to Mental Illness and Mental Deficiency's report had been published in 1957. Mills considered the key questions: 'what does community care mean?' and 'what does it mean to be a psychotic living in our society, or his relative?'<sup>20</sup> She explored the extent to which care was being provided for the mentally ill within their homes and whether this was in conjunction with professional help, support, and advice. The study was based on interviews with patients admitted to Long Grove Hospital, Epsom between 1956 and 1957, and their relatives, ideally separately.<sup>21</sup> As the Institute had conducted extensive research into families in Bethnal Green, Mills was afforded a point of comparison by conducting her study in the locality. Interviews relating to eighty-six patients were conducted, with seventy-six patients and seventy-four

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<sup>19</sup> Ibid., p. 147-48.

<sup>20</sup> Mills, *Mental Illness*, p. 2.

<sup>21</sup> Ibid., p. 4.



relatives interviewed in total.<sup>22</sup> The initial two sections of the interview schedule were based on the patient's illness, and an account of the illness, respectively.

In the third part, the relative closest to the patient was asked to describe, from his own point of view, the onset of the illness, his relationship with the doctor and the hospital, his own attitude towards the patient's illness and its treatment, and any difficulties he had encountered caring for the patient at home.<sup>23</sup>

Mills' 'study was designed to explore the role of the mentally ill in their family and community'.<sup>24</sup> Mills was concerned first and foremost with the experiences of patients themselves rather than those of caring relatives, but her interview schedule was designed to foreground the 'own account', 'own point of view', and 'own attitude' of the patients and relatives interviewed.<sup>25</sup> At the heart of her study was the objective of the patient being treated as an individual through families and services working together in a way which would best achieve this goal.<sup>26</sup>

However, the experiences of families caring for their mentally ill relatives do feature in Mills' publication. She states that 'on the whole, whether they were single, married, or widowed' . . . 'most of the patients were, wholly or partly, cared for by families and lived either with them or near them'.<sup>27</sup> This was a departure from the rhetoric of social policy documents from the 1940s and 1950s, which tended to recognise and encourage a role for the family in the care of mental

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<sup>22</sup> Ibid., p. 4. Three patients were not represented in the study because they, and their relatives, refused to be interviewed.

<sup>23</sup> Ibid., p. 5.

<sup>24</sup> Ibid., p. 7.

<sup>25</sup> Ibid., p. 5.

<sup>26</sup> Ibid., pp. 157-58.

<sup>27</sup> Ibid., p. 81.

handicap, but never explicitly mentioned the familial care of mental illness. This divergence in advice was evident in the 1954-57 Royal Commission on the Law Relating to Mental Illness and Mental Deficiency, which stated that:

there are various forms of care specially intended to help mentally disordered adults or children or to prevent mental illness. These include . . . advice to the parents of mentally defective children on how to care for them and help them to make the most of their limited abilities . . .<sup>28</sup>

In addition to a lack of acknowledgement of familial care for the mentally ill, evidence to the Royal Commission supported the marginalisation of the nearest relative's role in the certification process, recommending 'procedures when compulsion is used to override the unwillingness of the patient's relatives'. Whilst this quotation did not explicitly refer to care provided in the family home it does suggest instances of familial resistance to institutional care.<sup>29</sup>

However, Mills questioned the ability and appropriateness of families providing effective care. Concern was expressed over the reluctance of working-class families to seek treatment as 'some . . . patients . . . seem to have been kept out of hospital until they have reached a state of regression in which they may need much physical as well as mental nursing'.<sup>30</sup> 'Such families are liable to be at odds with authority, and do everything possible to shield members with mental or other

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<sup>28</sup> *Report of the Royal Commission on the Law Relating to Mental Illness and Mental Deficiency, 1954-1957* (London, 1957), p. 30.

<sup>29</sup> *Ibid.*, p. 14, p. 164.

<sup>30</sup> Mills, *Mental Illness*, p. 63, p. 90, p. 92.

troubles from outside influence'.<sup>31</sup> Sociologist Nick Crossley has suggested that this reluctance to seek outside help may be related to the stigmatisation of mental illness.<sup>32</sup> Further, Mills argued that working-class families were less likely to consider the care of a mentally ill relative as a burden, unless they faced financial difficulties, tending to rely on their own community support networks rather than opting to 'use' institutional provision in the way that their middle-class counterparts would.<sup>33</sup> As argued later in this chapter, this finding was later corroborated by researchers from the Medical Research Council's Social Psychiatry Unit.

*Living with Mental Illness* introduced a more widespread concern with how the relationship between familial and professional care would manifest itself following deinstitutionalisation. *Mental Breakdown*, a pamphlet published by the National Association for Mental Health (NAMH, later MIND) in 1959, described a fictional female protagonist's experience of her husband's mental illness. 'Certainly she didn't seem to be able to do anything for him at home, and probably at this stage in his illness it was better for him and for the family that he should go away and have proper care and treatment' . . . 'the family may be his worst enemy now but it may well be his greatest ally when medical treatment has done all it can'.<sup>34</sup> Thus, the move towards community care encouraged contemporaries, including social scientists, to explore the place of the carer in mental health care and whether this could be considered 'proper' care. The distinction was made between familial

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<sup>31</sup> Ibid., p. 148.

<sup>32</sup> Nick Crossley, *Contesting Psychiatry: Social Movements in Mental Health* (London, 2006), pp. 74-5.

<sup>33</sup> Mills, *Mental Illness*, p. 96.

<sup>34</sup> NAMH, *Mental Breakdown: A Guide for the Family* (London, 1959), pp. 3-4.

care and the care provided by psychiatric and medical professionals.<sup>35</sup> In the years following the 1959 Mental Health Act, there was a tendency to consider the family as providing a supportive role in rehabilitative care within the home with assistance from social and mental health workers.<sup>36</sup> However, the need for life-long support for chronic patients was overlooked by the medical model which was preoccupied with acute mental illness - the so-called 'treatable borderlines'.<sup>37</sup>

Another aspect considered by Mills is relationships within the family and their impact on mental illness. Mills indicated that mothers were the most likely to have a close relationship with, and care for, the ill relative, particularly in the case of single sons with schizophrenia. This closeness could illicit jealous reactions from other family members. Indeed, Mills suggested the mother-child relationship could be 'morbid in its intensity', a point echoed by R.D. Laing's notion of the schizophrenogenic mother. In a further critique of the mother's influence, Mills decided to conclude her study with a quote from an interviewee, Mr Kerstein, who stated that 'the best kind of relationship is what you'd call fatherly care – like a father to a son or a brother to a brother', where the patient was treated as an individual.<sup>38</sup>

In 1962 *Living with Mental Illness* was reviewed by sociologist Kathleen Jones, a contemporary authority on the development of community care. Jones

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<sup>35</sup> Royal Commission (1957), pp. 9-10, p. 14, p. 211, pp. 128-30.

<sup>36</sup> NAMH, *Mental Breakdown*, p. 4.

<sup>37</sup> Peter Barham, *Closing the Asylum: The Mental Patient in Modern Society* (Harmondsworth, 1992), pp. 13-14; Vicky Long, "'Often there is a Good Deal to be Done, But Socially Rather Than Medically": The Psychiatric Social Worker as Social Therapist, 1945-70', *Medical History*, 55 (2011), p. 229; Roy Porter, 'Two Cheers for Psychiatry! The Social History of Mental Disorder in Twentieth Century Britain', in Hugh Freeman and German E. Berrios (eds), *150 Years of British Psychiatry: Vol. 2, The Aftermath* (London, 1996), p. 396; Barbara Taylor, 'The Demise of the Asylum in Late Twentieth-Century Britain: A Personal History', *Royal Historical Society*, 21 (2011), p. 200.

<sup>38</sup> Mills, *Mental Illness*, pp. 157-58.

asserted that the study 'is essentially a small-scale piece of empirical research, unrelated to any previous work, or to any general concepts in this field'. This is unsurprising given that Mills' work challenges Jones' 'institution to deinstitutionalisation and community care' narrative by suggesting that families had been providing care for their mentally ill relatives often with little or no interaction with professionals or mental health care services.<sup>39</sup> Indeed, in a 1961 article published in *Social Work: A Quarterly Review of Family Casework* and based on the research Mills had conducted in the late 1950s, she stated that immigrant families were more likely to go to hospital for psychiatric treatment than the local population. Mills argued that this was because 'the locally-born patients were so closely interwoven with their families and so attached to the community that they were cared for at home until their condition became too severe.'<sup>40</sup>

Another study by nurse, mother, and social scientist, Sheila Hewett considered the experiences of families, and in particular mothers, of cerebral palsied children. The study, *The Family and the Handicapped Child* (1970), was framed around home-based interviews with mothers. Whilst the research was commissioned and funded by the Spastics Society (later SCOPE), Hewett was keen to assert that the opinions in the report were the researcher's own.<sup>41</sup> In addition, Hewett was a researcher working with the Medical Research Council's Social Psychiatry Unit, which is the focus of the next section of this chapter, at the time she conducted and published this survey. Similarly to the ICS's study, an aim of

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<sup>39</sup> See: Kathleen Jones, *A History of Mental Health Services* (London, 1972); Kathleen Jones, *Mental Health and Social Policy, 1845-1959* (London, 1960).

<sup>40</sup> Enid Mills, 'Mental Patients and their Relatives in East London', *Social Work: A Quarterly Review of Family Casework*, 18:2 (April 1961), pp. 4-7.

<sup>41</sup> Sheila Hewett, *The Family and the Handicapped Child: A Study of Cerebral Palsied Children in their Homes* (London, 1970), p. 7, p. 15, pp. 22-23.

Hewett's research was to consider the experiences of mothers with a cerebral palsied child, comparing this with families with normal children. Therefore Hewett structured her research in line with the methodology employed by, and compared her results with the findings of, a survey of Nottingham mothers by John and Elizabeth Newson conducted in 1963 and 1968.<sup>42</sup> As a result, Hewett's research findings were more meaningful and scientifically rigorous. Thus, because her findings could be compared with those of the Newsons' and the broader contemporary literature on parenting, her research had more tangible policy outputs.

Hewett interviewed 180 families in the East Midlands, with a focus on Nottingham, both because this was the base of the Spastics Society and since it was a similar geographical area to the one studied by the Newsons. Also like the Newsons, Hewett adopted a sociological, rather than a psychological, approach to the study of child development.<sup>43</sup> The two studies shared another commonality, in that they both actively set out to include the perspective of their object of study in their social research project. The Newsons' 'concentrated upon looking at the process of child rearing through the eyes of ordinary mothers'.<sup>44</sup> Similarly, Hewett aimed to dispel mythology surrounding the lives of families with a handicapped child by choosing to 'only present the picture given by the parents themselves of how they actually learn to live with a handicapped child.'<sup>45</sup> As Hewett wrote:

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<sup>42</sup> Ibid., p. 13.

<sup>43</sup> This was part of a broader trend at the time. Mathew Thomson, *Lost Freedom: The Landscape of the Child and the British Post-War Settlement* (Oxford, 2013), pp. 133-34. For more on John and Elizabeth Newson see: John Newson and Elizabeth Newson, 'Taking People Seriously: Psychology as a Listening Ear', in G. Bunn, A.D. Lovie, and G.D. Richards (eds), *Psychology in Britain: Historical Essays and Personal Reflections* (Leicester, 2001), pp. 411-21; Thomson, *Lost Freedom*, pp. 133-52.

<sup>44</sup> John and Elizabeth Newson, *Seven Years Old in the Home Environment* (London, 1976), pp. 15-16.

<sup>45</sup> Hewett, *The Family*, pp. 13-14.

There is no shortage of literature and comment about the problems which can beset the handicapped child and his family, . . . but not much is said about the families who meet the crisis of handicap, as they meet other crises, with resilience and common sense.<sup>46</sup>

She felt that this would improve professional understandings of familial experiences and act as a means of support for others in similar situations.<sup>47</sup> In this respect Hewett's work was part of a broader body of social scientific research which aimed to democratise social research at this time.<sup>48</sup> Typifying this, the publication included direct quotations from mothers. For example the mother of a four-year-old boy explained: 'actually, my mother and I had a terrific row, you see. She told me I should let him go away, you see, permanently, and I said I wasn't going to. She didn't speak to me for six months.'<sup>49</sup>

In terms of gender, Hewett stated that fathers cared for handicapped children to the same extent that they would care for 'normal' children.<sup>50</sup> However, some of the mothers interviewed 'considered that their husbands had found it harder than they had themselves to overcome their grief at having [a handicapped] child.'<sup>51</sup> Though Hewett also pointed out that mothers felt more pressure to accept their child's handicap.<sup>52</sup> Mothers were liable to feel depressed, predominantly

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<sup>46</sup> Ibid., p. 13.

<sup>47</sup> Ibid., pp. 13-14.

<sup>48</sup> Catherine Marsh, 'Informants, Respondents and Citizens', in Martin Bulmer (ed.), *Essays on the History of British Social Research* (Cambridge, 1985), pp. 206-27; Townsend, 'Surveys', pp. 228-35.

<sup>49</sup> Ibid., p. 125.

<sup>50</sup> Ibid., p. 107.

<sup>51</sup> Ibid., p. 104.

<sup>52</sup> Ibid., p. 200.

because they tended to stay at home with the child and lacked respite care.

Mothers who accepted respite care or went to work were less likely to say they were depressed.<sup>53</sup>

In contrast with Mills' conclusions, Hewett asserted that the lives of families with handicapped children were not too dissimilar to those with normal children. Hewett was able to draw this conclusion by cross-referencing with the work of the Newsons. Yet she also pointed out that families with handicapped children were more likely to contact, or elicit concern from, social work agencies.<sup>54</sup> In terms of service provision suggestions, Hewett promoted the use of social workers both to detect and supply the needs of families and supported enhanced communication between families and medical professionals.<sup>55</sup> Historian Deborah Cohen has argued that during the Victorian era professionals felt optimistic that the intellect of handicapped children could be 'improved'. As such, handicapped children in the Victorian period were more accepted into society and were not hidden away within their families. In contrast, in the inter-war years handicapped children, even when living at home, which was often the case in working-class families, were rarely seen in public owing to increased stigma and dwindling optimism for effective treatment. This began to change, Cohen argues, with the inception of the National Society for the Parents of Backwards Children in the 1940s.<sup>56</sup> Hewett's study, then, should be seen as capturing a world in which the boundary between handicapped children in

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<sup>53</sup> Ibid., pp. 70-1.

<sup>54</sup> Ibid., p. 154.

<sup>55</sup> Ibid., p. 161, p. 172.

<sup>56</sup> Deborah Cohen, *Family Secrets: Living with Shame from the Victorians to the Present Day* (London, 2013), pp. 77 -112.



the home and the outside world was breaking down. Hewett was encouraging that breakdown.

Mills' and Hewett's studies are indicative of moves towards uncovering the phenomenon of familial care for the mentally ill and mentally handicapped in the post-war period. The place of the family in mental health care was becoming of interest to researchers of both the mentally ill and the mentally handicapped at a similar time. Whilst the history of mental illness and mental handicap has often been studied separately by historians, both mental illness and mental handicap were being deinstitutionalised from the early 1960s onwards. As such, both became the subject of social studies about the family and community care in the 1960s and early 1970s.

By interviewing families directly and disseminating their findings not only to professionals and policy makers, but also to other families and the wider public, these social scientists played a role in helping to create and shape the role of familial care-givers. Mills and Hewett were interested in finding out more about the mentally ill and mentally handicapped children, respectively, but their research studies also provided an illuminating insight into the experiences of caring relatives. Mills was struck that working-class families were less likely to consider care-giving to be burdensome, whilst Hewett found that mothers were more likely to provide care for handicapped children than fathers. Gender and class continued to be used by social scientific researchers as defining characteristics of family care-givers throughout the post-war years.

## Expressed Emotion, c. 1958-1985

In the *Lancet* in 1958 researchers from the Medical Research Council's (MRC) Social Psychiatry Unit (SPU) stated that 'perhaps it is not always beneficial for a schizophrenic to return to the close emotional ties of a parental or marital household.'<sup>57</sup> This thesis developed into a theory of 'expressed emotion' in which the SPU found a correlation between high 'emotional involvement' homes and the 'deterioration of the patient.'<sup>58</sup>

Researchers working on expressed emotion at the SPU shaped the ways that the families of the mental ill and mentally handicapped came to be understood and written into social policy during the post-war period. Expressed emotion became a measure of stressful family relationships and home environments, the prevention of which could reduce the risk of mental illness and promote well-being.<sup>59</sup> Triggered by their research into the discharge of long-stay patients from mental hospitals prior to the supposed landmark 1959 Mental Health Act, SPU researchers came to study the social environment of the family, from which developed a more acute concern about the well-being of caring and supportive relatives.

Social Psychiatry had its origins in the group psychiatry that emerged during the Second World War as a method to more effectively treat soldiers suffering from mental illness, with a view to decreasing absenteeism.<sup>60</sup> In a wartime context, the

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<sup>57</sup> G.W. Brown, G.M. Carstairs and G.C. Topping, 'The Post Hospital Adjustment of Chronic Mental Patients', *Lancet*, 2:7048 (1958), p. 687.

<sup>58</sup> Liz Kuipers, 'Expressed Emotion: A Review', *British Journal of Social and Clinical Psychology*, 18 (1979), p. 237.

<sup>59</sup> Mark Jackson, *The Age of Stress: Science and the Search for Stability* (Oxford, 2013), p. 3, p. 11.

<sup>60</sup> John Crammer, 'The Impact of World Events: 1941-1950', in Hugh Freeman (ed.), *A Century of Psychiatry* (London, 1999), p. 124.

limitations of psychotherapy became evident; 'it was impossible to give individual psychotherapy to all patients who needed it'.<sup>61</sup> In Britain, where social psychiatry became a part of mainstream psychiatry, this particular trajectory developed in a number of different directions. Social psychiatry developed from and during the contexts of wartime concern for the ability of the population to work, the emergence of the welfare state, and the move towards community care.<sup>62</sup> The popularity of social psychiatry was part of a broader contemporary interest in social relationships and the psychosocial. Yet, social psychiatry is too loose a category for meaningful analysis without focusing on a particular manifestation of the approach. Indeed, contemporaries including the psychiatrist Michel Shepherd commented that social psychiatry was 'poorly defined' not least because of the tendency to misuse the word 'social'.<sup>63</sup> Whilst some, including the prominent social psychiatrist Maxwell Jones, came to focus on the development of therapeutic communities, others, including the MRC's SPU, focused their research on the social environment of the community.

Initially founded as the Occupational Research Unit in 1948 under the directorship of psychiatrist Aubrey Lewis, the MRC's Unit changed its name to the Unit for Research in Occupational Adaptation in 1951. In 1958 it became the Social Psychiatry Unit, with a new director, psychiatrist John Wing, taking the helm in

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<sup>61</sup> WL, *The Expanding Field of Mental Health in England and Wales, 50 years of progress, 1918-1968*, MS.7913/43, Joshua Bierer, *Some Developments in Social Psychiatry in Britain*, (1968), p. 2; Thomson, *Psychological Subjects*, p. 229.

<sup>62</sup> Hugh L. Freeman, 'The General Hospital and Mental Health Care: A British Perspective', *The Milbank Quarterly*, 73:4 (1995), pp. 653-76; Maxwell Jones, *Social Psychiatry in Practice: the Idea of the Therapeutic Community* (Harmondsworth, 1968); Porter, 'Two Cheers!', pp. 383-404.

<sup>63</sup> Michael Shepherd, *Conceptual Issues in Psychological Medicine* (2<sup>nd</sup> edn, London, 1998), p. 152.

1965.<sup>64</sup> The change in name reflected a change in emphasis as the Unit moved from a specific interest in the 'rehabilitation of mental retardation and aspects of occupational psychology into the field of social psychiatry in its broadest sense'.<sup>65</sup> However, occupational psychology and rehabilitation continued to be included within the Unit's remit.<sup>66</sup> Along with a broader interest in social psychiatry came a focus on mental illness, mental handicap, and the family, which would ultimately contribute to the development of the concept of the carer.

The SPU, characteristic of the wider MRC, opted to take a multidisciplinary approach to their research drawing heavily upon sociological methodologies. As Aubrey Lewis himself reflected:

Boundaries between branches of knowledge are vicious if they hinder true research; it is therefore, I think, proper . . . [to] use at once social, psychological and clinical psychiatric methods and modes of thought to throw light on problems not obviously or traditionally included in psychiatry, but likely to be illuminated by such study.<sup>67</sup>

The MRC's approach allowed researchers to ask new questions using new methods. The SPU, along with other medical and health professionals at the time, borrowed social science methodologies to explore the epidemiological relationship between

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<sup>64</sup> Paul E. Bebbington, 'Introduction: The MRC Social Psychiatry Unit and the World of Social Psychiatry', in Paul E. Bebbington (ed.), *Social Psychiatry: Theory, Methodology, and Practice* (New Brunswick, 1991), p. x.

<sup>65</sup> Bebbington, 'Introduction', p. x.

<sup>66</sup> For more on industrial psychiatry and rehabilitation, see: Vicky Long, 'Rethinking Post-War Mental Health Care: Industrial Therapy and the Chronic Mental Patient in Britain', *Social History of Medicine*, 26:4 (2013), p. 738-58.

<sup>67</sup> Aubrey Lewis, 'Social Aspects of Psychiatry', *Edinburgh Medical Journal*, 58 (1951), pp. 214-47.

social factors and illness.<sup>68</sup> Social factors were not only measurable, but were thought to have a significant role in the production and sustainment of illness.<sup>69</sup> Indeed, although the Social Psychiatry Unit was mainly staffed by psychiatrists, many of their initial studies into the relationship between the family and schizophrenia were co-authored by sociologist George Brown.<sup>70</sup> Brown had graduated in 1951 from University College London with a degree in archaeology and anthropology and was approached by George Morris Carstairs to work for the SPU in 1956 after working as a social researcher investigating mental patients being resettled into the community. In contrast to the methodological approach of those working for the Institute of Community Studies, Brown thought that a predominantly quantitative approach, in conjunction with semi-structured interviews, could provide greater insight into the emotions and psychological interactions than focused interviews.<sup>71</sup>

In line with other MRC Research Units at the time, including the Social Medicine and Epidemiology Units, the Social Psychiatry Unit was preoccupied with social and epidemiological factors, in addition to the more expected clinical factors, as a route to better understanding mental illnesses and mental handicaps. This should be understood in the broader context of shifts towards social understandings of mental illness and enthusiasm for social treatments and

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<sup>68</sup> Thomson, *Psychological Subjects*, p. 243.

<sup>69</sup> Armstrong, 'Medical Sociology', p. 1655.

<sup>70</sup> David Pilgrim and Anne Rogers, 'Social Psychiatry and Sociology', *Journal of Mental Health*, 14:4 (August 2005), p. 317.

<sup>71</sup> Rhodri Hayward, Rhodri Hayward, 'Sadness in Camberwell: Imagining Stress and Constructing History in Postwar Britain', in David Cantor and Edmund Ramsden (eds), *Stress, Shock, and Adaptation in the Twentieth Century* (Rochester, 2014), p. 324, p. 326.

therapies.<sup>72</sup> As outlined in a progress report published in 1973, the SPU's main research areas were: the causes of mental illness; the effectiveness of psychiatric services; the value of rehabilitation; the clinical nature of schizophrenia and autism; and, most importantly for this story, the effects of social environments, including the family home, on the course of schizophrenic illness.<sup>73</sup> In addition to obtaining a better understanding of mental illness and mental handicap, the SPU intended to affect political and social change via the use of interdisciplinary, experimental, and cutting-edge research methods.<sup>74</sup> It follows that once the SPU had gained insight into the place of the family in mental health care that its work would be utilised to illuminate and mediate the role of the carer.

The SPU changed its name in 1958 at a key moment in the history of post-war mental health care. The new name reflected the Unit's new interest in social psychiatry which, still included but also, extended beyond rehabilitative and occupational psychology.<sup>75</sup> With a view to influencing 'local service planning', the SPU, which was affiliated with the Institute of Psychiatry, conducted an epidemiological study of chronic conditions. The study was initiated by Morris Carstairs when he set up the Camberwell cumulative case register in 1964, which

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<sup>72</sup> Vicky Long, "Often there is a Good Deal to be Done, But Socially Rather Than Medically." The Psychiatric Social Worker as Social Therapist, 1945-70', *Medical History*, 55 (2011), pp. 223-39.

<sup>73</sup> The Wellcome Library, Rudolph Karl Freudenberg, PP/RKF/E.6/2, R. K. Freudenberg, *Social Psychiatry Unit Progress Report: Recent Research in Social Psychiatry*, Institute of Psychiatry, London (January 1973), p. 2.

<sup>74</sup> Matthew Smith has made this argument for the American context: Matthew Smith, 'Psychiatry Limited: Hyperactivity and the Evolution of American Psychiatry, 1957-1980', *Social History of Medicine*, 21:3 (2008), pp. 454-455. See also: J.K. Wing, 'Social Psychiatry', in Paul E. Bebbington (ed.), *Social Psychiatry: Theory, Methodology, and Practice* (New Brunswick, 1991), p. 19.

<sup>75</sup> Bebbington, 'Introduction', p. x.

became a key element of SPU research.<sup>76</sup> A response to seemingly embryonic community care initiatives, the register was facilitated by a cohort of newly discharged patients upon which the register was initially based. Rather than just focusing on the mentally ill, the register was also interested in other aspects of psychiatry, including what they termed mental retardation. The register, which continued to be compiled until 1999, provided demographic, social, and clinical data about those Camberwell residents who were in contact with a range of psychiatric services including out-patient clinics and local practitioners.<sup>77</sup> Envisioned as 'a kind of social laboratory' Camberwell, London, was chosen because of its proximity to the Maudsley and Bethlem Royal joint hospital which had links to the Institute of Psychiatry, and because it would provide a 'defined geographical area' to refine methodological techniques and measure change over time.<sup>78</sup> With a population of 175,000 inhabitants in 1971, Camberwell was a predominantly working-class area of London.<sup>79</sup> This methodological decision continued the tradition of the Institute of Community Studies, which also focused on a particular area – Bethnal Green, London - to facilitate the measure of change over time.

Whilst the Camberwell register was the cornerstone of much of the SPU's research, of more importance to the study of the emergence of the carer is the SPU's interest in the more specialised research area of the relationship between expressed emotion and schizophrenia. Three initial studies dealing with expressed

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<sup>76</sup> George W. Brown, 'The Discovery of Expressed Emotion: Induction of Deduction?', in Julian Leff and Christine Vaughn (eds), *Expressed Emotion in Families: Its Significance for Mental Illness* (London and New York, 1985), p. 9.

<sup>77</sup> Ransom J. Arthur, *An Introduction to Social Psychiatry* (Harmondsworth, 1971), pp. 58-9.

<sup>78</sup> J.K. Wing, 'The Camberwell Register and the Development of Evaluative Research', in J.K. Wing and Anthea M. Hailey (eds.), *Evaluating a Community Psychiatric Service: The Camberwell Register, 1964-71* (London, 1972), pp. 4-5.

<sup>79</sup> Arthur, *Social Psychiatry*, pp. 58-9.

emotion and schizophrenia began in 1956, 1959, and 1967. The first study began in the same year as Mills' research and was concurrent with the research period for the Royal Commission (1954-57).<sup>80</sup> Significantly, although the study preceded the 1959 Mental Health Act and Enoch Powell's 1961 Water Tower speech it was facilitated by 'discharged chronic male patients who happened, against all odds, to have left the hospital'.<sup>81</sup>

Building upon a prior interest in industrial rehabilitation, the SPU's researchers were particularly interested in individuals who could not 'undertake regular work', whether due to having a 'very limited intelligence (IQ 20-50) . . . or suffering from the impairments of chronic schizophrenia'.<sup>82</sup> Owing to its unknown aetiology, chronic nature, high instance among discharged long-term patients, and the proportionally high instance of relapse among those with a diagnosis, schizophrenia made an ideal initial case study for the SPU to pursue. The researchers felt that a greater understanding of the impact of social environment on the course of the illness could improve treatment and reduce the risk of readmission.<sup>83</sup> Further, schizophrenia was attracting broader research interest at this time. As Brown himself explained, it was this interest in schizophrenia which initially led the SPU, if not to focus on the social environment of the family, then to interview relatives: 'our work from the start was aimed at using a relative as the

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<sup>80</sup> *Report of the Royal Commission on the Law Relating to Mental Illness and Mental Deficiency, 1954-1957* (London, 1957).

<sup>81</sup> Brown, 'Expressed Emotion', p. 9.

<sup>82</sup> Crammer, '1941-1950', p. 124.

<sup>83</sup> G.W. Brown, E.M. Monck, G.M. Carstairs, and J.K. Wing, 'Influence of Family Life on the Course of Schizophrenic Illness', *British Journal of Preventative and Social Medicine*, 16 (1962), pp. 55-68; G.W. Brown, J.L.T. Birley, and J.K. Wing, 'Influence of Family Life on the Course of Schizophrenic Disorders: A Replication', *British Journal of Psychiatry*, 121 (1972), pp. 241-258.



main source of information and our common experience of finding the patients often uncommunicative reinforced this'.<sup>84</sup>

It was the findings of the SPU's explanatory research (1958) which reinforced this focus on relatives as conduits of the patient's experience, as it 'found that close emotional ties with parents or wives indicated poor prognosis' and that 'patients apparently did well even if unemployed, as long as their mothers went out to work'.<sup>85</sup> The SPU then conducted increasingly expansive follow-up studies, some of which focused specifically on the social environment of the family home. The SPU's 1962 'landmark' study included interviews with relatives for the first time and in 1966 the term 'expressed emotion' emerged. The SPU's studies during the 1970s and 1980s were characterised by a clearer focus on the experiences and problems of relatives of those with schizophrenia, suggesting practical solutions and potential interventions.<sup>86</sup> Further, SPU researchers began to focus on other conditions, in particular neurotic depression.<sup>87</sup> The growing tendency of SPU researchers to consider the effects and problems of relatives, especially from the early 1970s onwards, demonstrates that SPU researchers were developing an ever greater knowledge of the previously hidden world of mental illness and mental handicap within the family. The SPU was interacting with a wider discourse, also found in the work of Mills and Hewett, relating to the ability, or indeed inability, of relatives to become effective care-givers. As funding for its

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<sup>84</sup> Brown, 'Expressed Emotion', p. 12.

<sup>85</sup> Brown, 'Expressed Emotion', p. 15; Brown, Birley, Wing, 'Schizophrenic Disorders', p. 241.

<sup>86</sup> David Kavanagh, 'Recent Developments in Expressed Emotion and Schizophrenia', *British Journal of Psychiatry*, 160 (1992), pp. 614-15.

<sup>87</sup> C.E. Vaughn and J.P. Leff, 'The Influence of Family and Social Factors on the Course of Psychiatric Illness: A Comparison of Schizophrenic and Depressed Neurotic Patients', *British Journal of Psychiatry*, 129-137, pp. 125-137.

research increased, the SPU was able to develop 'new measures of family life' which were incorporated into the 1972 survey.<sup>88</sup>

Building upon the widespread contemporary belief that care *in* the community would mean care *by* the family in reality, it would seem that the SPU's researchers became interested in the reciprocal relationship between the family, the family home, and those diagnosed with schizophrenia, and later other conditions, predominantly in response to contemporary rhetoric and concern.<sup>89</sup> However, Brown reflected in 1985 that the SPU utilised retroductive logic, which involved a combination of inductive and deductive approaches:

We probably only collected information about living groups at discharge because it was the kind of thing that social scientists would be expected to concern themselves with. It did not come from a theory about schizophrenia, but from some dim recognition of what social scientists such as ourselves should be considering.<sup>90</sup>

Once Brown and his fellow researchers found that '*something* about family relationships was important', and faced with a dearth of relevant sociological studies, they began to develop indicators of expressed emotion.<sup>91</sup>

The surveys developing out of the Camberwell register were designed to include interviews with patients and a key relative, usually a mother, wife, or husband, to ascertain whether family environment was a factor in early relapse and

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<sup>88</sup> Brown, 'Expressed Emotion', p. 9.

<sup>89</sup> Brown, Birley, Wing, 'Schizophrenic Disorders', pp. 255-56.

<sup>90</sup> Brown, 'Expressed Emotion', p. 13, pp. 16-18.

<sup>91</sup> *Ibid.*, p. 19, p. 23.

readmission of discharged long-stay patients. Relatives who took part in the Camberwell Family Interviews were interviewed in their own homes with the prime objective of testing the Unit's 'expressed emotion' thesis. One of the key findings of the 1962 study, which tended to be replicated by subsequent SPU research, was that 'patients returning to a relative who showed "high emotional involvement" (based on measures of "expressed emotion", hostility, and dominance) would deteriorate more frequently than patients returning to a relative who showed "low emotional involvement"'.<sup>92</sup> 'The more neutral term' expressed emotion was used as a short-hand for this phenomenon from 1966 onwards.<sup>93</sup>

As earlier studies had struggled to establish 'in which direction cause and effect lay', the 1972 study was designed so that the patient and family were interviewed eight times, or ten if the patient was readmitted to hospital.<sup>94</sup> Following an initial clinical interview with the patient upon admittance to hospital, the patient and their family were interviewed separately. Two weeks after discharge a joint interview was conducted with the patient and their family before separate follow-up interviews after nine months of discharge or earlier if the patient was readmitted.<sup>95</sup> As explained in the SPU's 1973 progress report, 'the most measurable component of expressed emotion [was] the number of critical comments by the key relative about the patient. This factor, measured at the time

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<sup>92</sup> Brown, Monck, Carstairs, and Wing, 'Schizophrenic Illness', pp. 65-66; G.W. Brown, Margaret Bone, Bridget Dalison, and J.K. Wing, *Schizophrenia and Social Care: A Comparative Follow-up Study of 339 Schizophrenic Patients* (London, 1966), pp. 7-8.

<sup>93</sup> Brown, 'Expressed Emotion', p. 9.

<sup>94</sup> PP/RKF/E.6/2, *Social Psychiatry*, p.6.

<sup>95</sup> Brown, Birley, Wing, 'Schizophrenic Disorders', pp. 242-43.

of key admission was strongly associated with symptomatic relapse during the follow-up period'.<sup>96</sup>

Although taking into consideration both the positive and negative influence of expressed emotion in previous studies, by the early 1970s the concept was considered by SPU researchers to have 'a mainly negative connotation'.<sup>97</sup> According to psychologist David Kavanagh, who reviewed the SPU's findings in 1992, 'families and health researchers . . . expressed concern that [expressed emotion] may be used to blame families for the disorder'.<sup>98</sup> This is unsurprising given the popularity of the literature of those associated with the anti-psychiatry movement in the 1960s and 1970s, which considered schizophrenia to be the product of over bearing, or schizophrenogenic, parents, usually mothers.<sup>99</sup> The term schizophrenogenic was used by R.D. Laing to describe the phenomenon of mothers, and later families, causing schizophrenia.

However, SPU reports explicitly contradicted the views of those associated with anti-psychiatry and Wing was actively involved with the National Schizophrenia Fellowship at the time, an organisation which was vehemently anti-anti-psychiatry.<sup>100</sup> As Brown himself wrote in 1985: 'I was skeptical [*sic*] about the published discussions of the role of family relationships in the etiology [*sic*] of schizophrenia.'<sup>101</sup> Indeed, the 1962 study noted that:

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<sup>96</sup> PP/RKF/E.6/2, *Social Psychiatry*, pp. 6-7.

<sup>97</sup> Kavanagh, 'Recent Developments', p. 601.

<sup>98</sup> *Ibid.*, p. 601 and p. 613.

<sup>99</sup> For more on anti psychiatry, see Chapters Three and Five of this thesis.

<sup>100</sup> Crossley, *Contesting*, p. 5.

<sup>101</sup> Brown, 'Expressed Emotion', p. 21.

In the light of present knowledge, it should not be too readily assumed that the parents' handling of the patient when a child has caused schizophrenia to develop; such an assumption may be wrong, in which case harm may be done both to relative and patient.<sup>102</sup>

Further, in 1966 social psychiatrists G.W. Brown, Margaret Bone, Bridget Dalison, and J.K. Wing, noted that R.D. Laing and Aaron Esterson's seminal work *Sanity, Madness, and the Family* (1964) did not 'have sufficient empirical foundation to be useful in planning services.'<sup>103</sup> Moving beyond previous work, and the concurrent work of the anti-psychiatry movement, which had focused on the relationship between parent and child, the Unit was also interested in the relationship between adult patient and parent, and indeed other relationships, including those between spouses. As Kavanagh reflected in 1992:

In place of a unidirectional influence from relatives to patients, the [SPU's] model explicitly recognise[d] the inter-relationship of patient's behaviour and the reactions of relatives, and [considered expressed emotion] as an understandable response to the difficulties that schizophrenia pose[d] to the family.<sup>104</sup>

Rather than alienating the family, as the anti-psychiatry movement was thought by some to be doing, the SPU hoped to include the family, and indeed the patient and

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<sup>102</sup> Brown, Birley, Wing, 'Schizophrenic Disorders', p. 256.

<sup>103</sup> Brown, Bone, Dalison, and Wing, *Schizophrenia*, p. 215.

<sup>104</sup> Kavanagh, 'Recent Developments', p. 613.

the wider community, in the therapeutic process.<sup>105</sup> The family could serve as the solution to mental illness, but too much emotion in the family could also be a causal factor in onset and relapse. Concurrent research, including studies by child psychologist John Bowlby, emphasised the importance of love and attachment for child development.<sup>106</sup> The SPU agreed that a loving atmosphere was important, but felt that short periods of separation were also healthy. However, others considered an excess of emotion to be the product and cause of stress and ill-health within the family.<sup>107</sup> The age of onset for schizophrenia was usually late adolescence or early adulthood, at a life-stage when children were expected by some, including Laing, to become independent of their parents. The SPU stressed that this was neither always possible, nor beneficial in the case of schizophrenia. Cohen has suggested that by the 1970s the 'autonomy of the individual' was preferable to 'the unbreachable sanctity of the familial sphere.'<sup>108</sup> Whilst, as supporters of studies of the family and family therapy, the SPU cannot be said to have promoted the privacy of family life, the Unit did not consider the needs of the mentally ill relative as superseding the needs of the broader family.

The SPU was keen to provide support to relatives to temper the implications of expressed emotion. The SPU noted in its 1962 survey that there was a 'wide variation in the response of relatives to the same kind of psychotic behaviour'.<sup>109</sup> Two main factors were offered to explain this difference: firstly, an assertion that a

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<sup>105</sup> Brown, Birley, Wing, 'Schizophrenic Disorders', pp. 256-57; John Pringle, 'Breaking an Old Taboo', *The Times*, 26 June 1980, p. 18.

<sup>106</sup> John Bowlby, *Child Care and the Growth of Love* (2nd edn, Harmondsworth, 1965).

<sup>107</sup> Jackson, *Stress*, p. 3, pp. 10-11. Stress had become established as an area of academic research by the late 1950s: Cary L. Cooper and Philip Dewe, *Stress: A Brief History* (Oxford, 2004), p. 39.

<sup>108</sup> Cohen, *Family Secrets*, pp. 234-35.

<sup>109</sup> Brown, Monck, Carstairs, and Wing, 'Schizophrenic Illness', p. 64.

lesser degree of personal contact between patient and relative could increase family tolerance; and secondly, class. The SPU's 1972 publication strongly recommended active intervention in the family by psychiatric professionals. For instance, limiting face-to-face contact with highly emotional relatives, perhaps via the use of day centres, would decrease the chance of relapse.<sup>110</sup> In this respect, the Social Psychiatry Unit demonstrated a continued interest in rehabilitative occupational psychology, with the additional benefit of decreasing contact with high involvement relatives. The awareness of the potential problems arising from living within the family home also helps to explain Wing's protestations against mental hospital closures, where those suffering from schizophrenia could seek refuge during times of crisis.<sup>111</sup> However, the minimisation of face-to-face contact would have proved difficult without the co-operation of both patient and relative.

One way of encouraging co-operation between professionals, patients, and relatives was via carer organisations. SPU researchers John Wing and his wife and fellow psychiatrist Lorna Wing, were involved in the National Schizophrenia Fellowship (NSF) and the National Autism Society (NAS) respectively. The willingness of the Unit to consider the family's perspective should not be seen only in the context of social psychiatry, but also in light of the personal context of John and Lorna Wing. The Wings' daughter, Susie, born in 1956, was diagnosed with autism at the age of the three. This experience made the Wing's aware of the difficulties faced by families caring for a mentally ill or mentally handicapped relative and facilitated a blurring of the boundary between their interests as professionals and as parents. As SPU researchers had the scope to pursue their own

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<sup>110</sup> Brown, Birley, Wing, 'Schizophrenic Disorders', pp. 256-57.

<sup>111</sup> WL, PP/DSI/A/3/1, John Wing, *Where do we go from here?* (September 1984), pp. 1-4.

research interests, it is unsurprising that John and Lorna specialised in research on the experiences of families with a relative with schizophrenia and autism respectively.<sup>112</sup>

Owing to the Wings' involvement, the NSF and the NAS encouraged relatives to set up mutual support groups that would not be open to patients, as a means to increase socialisation of relatives and decrease the adverse effects of expressed emotion.<sup>113</sup> The involvement of relatives in these organisations encouraged caring relatives to identify themselves as carers. By becoming involved in the SPU's research, joining a carer group, or attending a relative's support group, family members were made aware of their status as the relative of someone with a mental disorder and the ways in which this role affected their life. These individuals shared their experiences and in doing so they formed what historian Barbara Rosenwein has termed an "'emotional community'".<sup>114</sup>

However, this realisation had a class dimension, with those from the middle-classes most likely to be actively aware of their role as a carer and actively involved in carer groups. In line with Mills' findings, SPU research found that families from working-class families were less likely to view their relationship to a mentally disordered relative as a burden, something unnatural, or to seek professional assistance. In 1974 the NSF commissioned an 'authoritative independent' survey by John Wing and Clare Creer, entitled *Schizophrenia at Home*, which compared the experiences of articulate middle-class NSF member families to a parallel, randomly

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<sup>112</sup> Bebbington, 'Introduction', p. x.

<sup>113</sup> PP/RKF/E.6/2, *Social Psychiatry*, p. 7.

<sup>114</sup> Barbara H. Rosenwein, 'Worrying about Emotions in History', *American Historical Review*, 107:3 (2005), p. 824.



selected group of working-class manual workers from the Camberwell Register.<sup>115</sup>

Whilst the National Schizophrenia Fellowship (NSF) was founded on the view that

having a relative with schizophrenia was a 'burden', working-class relatives from

the Camberwell sample were unlikely to view the relationship in these terms.

Indeed, in contrast to the NSF sample, the Camberwell sample were described as

'not yet noted for its awareness of consumer rights and tends to accept whatever is

provided without complaint.'

The survey strove 'to provide a factual description of the impact of schizophrenia on relatives' which could be subsequently used to spread awareness and influence social-policy decisions. A prime motive, and indeed conclusion, of the survey was to demonstrate that family members were the real primary care-givers for schizophrenia in the community in 1970s Britain. It was concluded that 'Fellowship members described more personal problems arising out of the presence of a patient in the home and were much less likely to be satisfied with the services provided.'<sup>116</sup> However, in the foreword to *Schizophrenia at Home*, psychiatrist Henry Rollin downplayed the difference between the two samples, explaining that these variations were largely arbitrary, and Wing and Greer argued that the two groups had similar experiences, although the Camberwell sample's were 'described less articulately'.<sup>117</sup> The study reflected on these similarities:

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<sup>115</sup> John Wing and Clare Greer, 'Schizophrenia at Home', in Henry R. Rollin (ed.), *Coping with Schizophrenia* (London, 1980), p. 17; Modern Records Centre (MRC), Central Council for Education and Training in Social Work, mss.422/3, National Schizophrenia Fellowship, *Schizophrenia at Home*, p. 52.

<sup>116</sup> MRC, *Schizophrenia at Home*, p. 52.

<sup>117</sup> Wing and Greer, 'Schizophrenia at Home', p. 18; MRC, *Schizophrenia at Home*, p. 52.

Most relatives [from both samples] referred to some form of emotional stress, though they differed in how articulate they were about this. But among the different descriptions . . . anxiety, guilt, depression, and anger were frequently mentioned.<sup>118</sup>

Also, 'several relatives mentioned the divisive effects of schizophrenia upon a family', with strains placed on relationships.<sup>119</sup>

By reflecting upon and expressing their emotional responses to, and experiences of, the care of relatives with schizophrenia, these relatives, and in particular those from the NSF sample who were more articulate, were interrogating and forming a sense of identity which was related to their role as care-givers. This identity could be said to have been gendered.<sup>120</sup> These gender differences were even more evident in *Schizophrenia at Home*, also published in 1974, which was a compilation of letters from NSF members detailing their family's personal experiences. These accounts, mostly written by mothers, refer to the inability of fathers to come to terms with their children's conditions, especially because of the stigma associated with schizophrenia.<sup>121</sup> However, one mother also explains that her son's wife is unable to 'accept that this is to be for life.'<sup>122</sup>

By accepting that not all relatives viewed their situation in terms of burden the SPU was able to negotiate the terminology related to the carer. In a chapter entitled 'The Role of Relatives' (1982), based upon more in-depth interviews with relatives, it was noted that:

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<sup>118</sup> MRC, *Schizophrenia at Home*, p. 30.

<sup>119</sup> Ibid., p. 36.

<sup>120</sup> Ibid., p. 1.

<sup>121</sup> Ibid., pp. 8-11, p. 42.

<sup>122</sup> Ibid., p. 41.

Earlier research in this field has used a distinction between objective and subjective 'burden' on relatives. The distinction is important because 'objective' is assessed without taking account of the relative's feelings of satisfaction or dissatisfaction. Since, however, relatives do not necessarily regard their tasks as burdensome, we prefer to use the more neutral term 'support' instead of 'objective burden'.<sup>123</sup>

The interviews conducted by Clare Creer and T. Wykes allowed the language often employed to describe family experiences to be problematised. The preference for using 'more neutral' terms suggests the role of the carer was acknowledged as a politicised issue. Further, the SPU was willing to adapt its research agenda to reflect the needs and experiences of these carers. As sociologist Catherine Marsh explained in 1985, the willingness to allow research subjects, in this case carers, to have a say over research agendas enhanced their rights and standing as citizens. This move, then, was in line with the view that carers should be seen as primary care-givers.<sup>124</sup> The SPU's 1982 report concluded that 'many patients depend on the care and support provided by relatives and friends as much as or more than on the help of services'.<sup>125</sup> As the relatives interviewed were unlikely to view this role as a burden the report asserted that 'it is therefore necessary to give as serious attention to the needs of supportive relatives in a "community care" system as to the needs of the patients'.<sup>126</sup> By the mid-1980s this rhetoric entered social policy

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<sup>123</sup> C. Creer, E. Stuart and T. Wykes, 'The Role of Relatives', in J.K. Wing (ed.), 'Long-term Community Care: Experience in a London Borough', *Psychological Medicine: Monograph Supplement 2* (Cambridge, 1982), p. 30.

<sup>124</sup> Marsh, 'Informants', p. 225.

<sup>125</sup> Creer, Stuart and Wykes, 'Relatives', p. 29.

<sup>126</sup> *Ibid.*, p. 38.

discourse, with the DHSS evidence to the House of Commons Committee on Social Services stating in 1985 that community care provision should aim 'to give support and relief to informal carers (family, friends and neighbours) coping with the stress of caring for a dependent person.'<sup>127</sup> However, it was not until the 1995, 2000, and 2004 Carers Acts that this aim became legislated for.

Thus, by the 1980s SPU's researchers came increasingly to view the experiences of carers as a subject worthy of inquiry in its own right. This research had an impact on the development and negotiation of understandings of the role of the carer because of the widespread interest in the concept of expressed emotion, culminating in the World Health Organisation's own survey.<sup>128</sup> However, this broader interest in expressed emotion research did not begin until the publication of Christine Vaughn and Julian Leff's research on neurotic depression in 1974.<sup>129</sup> As Leff and Vaughn reflected in 1985, they considered that their work had 'begun to influence ways of looking at families of psychiatric patients and of working with them clinically'.<sup>130</sup>

The SPU interacted with carers themselves, for example via carer groups, with the SPU's research being disseminated back to families themselves via these organisations' group meetings, publications, and newsletters. As the issues around the place of the family carer in mental health care became increasingly politicised, the SPU adopted a nuanced approach to the study of the experiences of these

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<sup>127</sup> Department of Health and Social Security, *Community Care: Agenda for Action. A Report to the Secretary of State for Social Services* (London, 1988), p. 5.

<sup>128</sup> D. Raune, E. Kuipers, and P.E. Bebbington, 'Expressed Emotion at First Episode Psychosis: Investigating a Carer Appraisal Model', *British Journal of Psychiatry* 184 (2004), pp. 321-26.

<sup>129</sup> Brown, 'Expressed Emotion', p. 10; Julian Leff and Christine Vaughn, 'Epilogue', in Julian Leff and Christine Vaughn (eds), *Expressed Emotion in Families*, p. 225.

<sup>130</sup> Leff and Vaughn, 'Epilogue', p. 226.

individuals by considering class differentials and adapting their research methodologies. Further, John Wing lobbied Parliament about the problems associated with the discharge of long-stay patients without adequate community provision being in place.<sup>131</sup> Thus, the SPU's research shaped the role of the family carer via social policy decisions but also by helping to give the relatives themselves a voice, albeit mediated by research agendas.

### **The General Household Survey: 1985, 1990, and 1995**

The state began to explicitly recognise the role of family care-givers in mental health care provision during the 1970s, demonstrated by the publication of the *Better Services* white papers.<sup>132</sup> Information on caring relatives was also collected during the application process to the Family Fund, which was set up in 1973 to help the families of children under sixteen with severe handicaps and serious illnesses. The Family Fund, which was set up in response to the thalidomide scandal, collected, and to a limited extent collated, information from families themselves, particularly in terms of the material needs of the children being cared for.<sup>133</sup> However, it was not until 1985 that the government sanctioned a wide scale social survey of familial carers themselves, with the inclusion of a section on 'informal carers' in the General Household Survey (GHS).

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<sup>131</sup> Vicky Long, 'Rethinking Post-War Mental Health Care: Industrial Therapy and the Chronic Mental Patient in Britain', *Social History of Medicine*, 26:4 (2013), p. 746.

<sup>132</sup> See Chapter One for a detailed analysis of the *Better Services* white papers.

<sup>133</sup> The National Archives (TNA), Ministry of Health and Department of Health and Social Security, MH154/756-62, Thalidomide, Joseph Rowntree Memorial Trust, *Proposals for Setting Up the Family Fund for Families of Handicapped Children*.

Established in 1971, the GHS was a continuous, cross-sectional sample survey conducted by the Office of National Statistics (ONS) to collect data via face-to-face and telephone interviews about private households in Britain, which informed government policy-making decisions. The sample size was c. 18,000 households for the 1985 and 1995 surveys. The intention of the surveys was to gather data which could be extrapolated to the whole of the population in the intervening years between decennial censuses. As Savage posits, developments in social scientific methodologies, which led to the introduction of annual repeat surveys in the 1970s (also including the Family Expenditure Survey and the New Earnings Survey), ‘allowed “accurate” assessments of change over time’, which could be mobilised ‘to develop accounts of the modern nation which were both sociological and administrative’.<sup>134</sup> Whilst the methodology of the survey changed over time the broad rationale behind the GHS remained unchanged. The government began to adopt social survey techniques as a means to better understand the population and the state of the nation at the very time the role of the carer was drawing attention, owing to moves towards a community care model and concerns over demographic change.<sup>135</sup>

The survey design could be changed every five years if a particular government department required extra information. In 1985 a new section was introduced to investigate the phenomenon of ‘informal carers’, on behalf of the Department for Health and Social Security (DHSS). Following a series of ‘more detailed local studies’ a section on ‘informal carers’ was included in the GHS of

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<sup>134</sup> Savage, *Identities*, p. 211.

<sup>135</sup> *Ibid.*, p. 189, p. 201.

1985. This was repeated again in 1990 and 1995.<sup>136</sup> Although the GHS report did not mention the specifics of these local surveys, the surveys mentioned earlier in this chapter would have either been influential, or indicative of a wider trend towards researching familial care at this time, including research into old age care. The ONS hoped the questions relating to informal care would ‘provide national estimates of the number of informal carers and to describe their characteristics’ in a context where ‘indications are that there will be continued growth in the overall demand for informal care’.<sup>137</sup> The speculated increase in the number of carers was perceived not only as a product of community care initiatives, but also demographic changes resulting from an impending ageing population and changes in family structure and women’s labour patterns.<sup>138</sup> This preoccupation with demographic change is demonstrated by a bias towards old age care in the GHS interview schedule, while other GHS sections introduced during the 1980s were also themed around old age and pensions. The informal carer section was therefore very much framed around the seemingly pressing issue of the ageing population, but the survey was also designed to ascertain the extent, and nature, of carers for those with mental illnesses and mental handicaps.

The 1985 survey’s questions were configured around the following research areas: prevalence of informal care; who is caring for whom?; nature of care; and who supports the carer? The 1995 survey also sought to establish time spent on caring activities. The survey’s interview questions were based on a working

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<sup>136</sup> Similar research is now conducted by The NHS Information Centre for Health and Social Care’s *Survey of Carers in Households in England*.

<sup>137</sup> Hazel Green, *Informal Carers: A Study carried out on behalf of the Department of Health and Social Security as part of the 1985 General Household Survey* (London, 1988), p. 4.

<sup>138</sup> Green, *Informal Carers*, p. 4.

definition of informal carer employed by the GHS. In both the 1985 and 1995 surveys informal carers were defined as: 'people who are looking after, or providing some regular service for, a sick, handicapped or elderly person living in their own or another household'.<sup>139</sup> In 1985 it was found that one in seven adults were providing informal care in one in five households, figures which were corroborated by the 1995 survey results, which found one in eight adults providing informal care in one in six households. The resultant reports postulated that there were six million carers in Britain in 1985 and 5.7 million carers in 1995.<sup>140</sup> This indicates that either the prospected increase in informal care had taken place before 1985 or that the number of informal carers in Britain had always been this prevalent.

However, the results of the 1990 survey of informal carers indicated that the number of respondents to the informal carer questions had increased, or 'spiked' in that year. Secondary analysis by GHS researchers suggested that this could have occurred because of 'real' changes. More likely it was a small change in question wording, the effects of an ageing population, or the high profile of carers resulting from the work of carer organisations. Secondary analysis of the survey surmised that 'there was a "growing division between those involved in heavy caring responsibilities and those who were largely 'helpers', providing relatively few hours of practical assistance"'.<sup>141</sup> Certainly, more people were self-identifying as carers by 1990, which in line with the arguments presented elsewhere in this thesis, was likely to be because of the growing visibility of, and benefits associated with, the

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<sup>139</sup> Green, *Informal Carers*, p. 1; Olwen Rowlands, *Informal Carers: An Independent Study Carried out by the Office for National Statistics as part of the 1995 General Household Survey* (London, 1998), p. vi.

<sup>140</sup> Green, *Informal Carers*, p. 1; Rowlands, *Informal Carers*, p. vi.

<sup>141</sup> Rowlands, *Informal Carers*, p. vii, p. 40.



label of carer by the late 1980s. The 1995 survey design reflected a refinement in the language utilised, with informal carers and informal helpers being distinguished from one another via questions to ascertain the number of hours spent caring each week.<sup>142</sup> Interestingly, then, the design, pilot, and follow-up stages of the survey design involved those creating and refining the section of the survey to define and redefine what it meant to be an informal carer.

It is important to note that the vast majority of those identified as informal carers by the GHS were caring for elderly relatives or those with physical disabilities. Interestingly, given the marginalised place of mental health care within broader welfare provision, a category for carers of the mentally disabled was factored into the survey design. The survey also elicited a consideration of the distinction between mental illness and mental handicap. The survey report stated that: 'although it is recognised that they have different needs', both groups were combined under the heading 'mentally disabled', in part because it was found during the pilot stage that 'many carers were unable to make the distinction'. It was noted that the old age category could also have included those with mental illness over a certain age.<sup>143</sup> So, in contrast to previous research by the Institute of Community Studies and the Social Psychiatry Unit, the General Household Survey included carers for the mentally ill, mentally handicapped, physically handicapped, and the elderly in a broad conception of the 'informal carer'. Finally, by 1995, hours spent caring, rather than the condition of the care recipient, was of central importance to the identification of an individual as an informal carer.

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<sup>142</sup> Ibid., p. viii.

<sup>143</sup> Green, *Informal Carers*, p. 19.

Before being reported to government departments, the results of the GHS were digested and analysed by researchers, in particular social scientists working at the Social Policy Research Unit at the University of York. Indeed, sociologist and political scientist Gillian Parker provided commentary within the 1995 survey report itself. The ONS's rationale was that this would set the 1985, 1990, and 1995 informal carers section results 'in the context of trends in caring from 1985-1990'.<sup>144</sup> As the Nuffield Professor of Community Care at the University of Leicester, Parker was well positioned for this task having already conducted research on families with disabled children in the 1980s before her involvement with the ONS.<sup>145</sup> Parker reflected in 1992 on the impact of the 1985 GHS:

Until 1988 . . . when information about informal care from the 1985 General Household Survey (GHS) was published, knowledge was patchy about the numbers and characteristics of those who support disabled and older people in the community on an informal basis.<sup>146</sup>

The survey's finding that there were c. six million carers in Britain 'promoted substantial comment and debate', for example into the gender (im)balance of caring and the activities of carers.<sup>147</sup> Parker's analysis within the 1998 report focused heavily on carers of old age. She concluded that 'the supply of informal

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<sup>144</sup> Rowlands, *Informal Carers*, p. v.

<sup>145</sup> For instance, see: Gillian Parker, 'Use of incontinence services by families with a disabled child', *International Journal of Rehabilitation Research*, 7:1 (1984), pp. 60-61; Gillian Parker, *With Due Care and Attention: A Review of Research on Informal Care* (London, 1985).

<sup>146</sup> Gillian Parker, 'Counting Care: Numbers and Types of Informal Carers', in Julia Twigg (ed.), *Carers: Research and Practice* (London, 1992), p. 6.

<sup>147</sup> Parker, 'Counting Care', p. 6. See Chapter One of this thesis for a more detailed examination of the relationship between gender and the General Household Survey research on informal care.

care will continue as a major policy concern for the future, particularly as the post-war “baby boomers” approach old age’. As this indicates, preoccupation with the population time bomb was a key factor in a continued focus on the phenomenon of the informal carer.<sup>148</sup>

In 1994 Parker, along with social scientist Dot Lawton, reflected on trends within informal care using GHS results. Parker and Lawton noted a paradox in that even once the role of the carer became visible, and social-policy changes were effected, this did not necessarily change anything for carers themselves: ‘[carers] are peripheral to the social care system . . . and yet they are essential to its functioning’.<sup>149</sup> Further,

The picture for informal carers, then, is mixed. On the one hand they are, for the first time, acknowledged as the major providers of ‘community care’; on the other hand, it remains difficult to see how much of existing and new resources will be given over to supporting or relieving them.<sup>150</sup>

Therefore whilst the GHS and other social scientific research made the role of the carer more visible and led to social policy change, this did not necessarily change the lot of carers themselves. Parker and Lawton suggested instead that it was important to reconsider definitions of care and to gain a better understanding of

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<sup>148</sup> Rowlands, *Informal Carers*, p. 47.

<sup>149</sup> Gillian Parker and Dot Lawton, *Different Types of Care, Different Types of Carer: Evidence from the General Household Survey* (London, 2004), pp. 3-4.

<sup>150</sup> *Ibid.*, p. 4.

caring activities.<sup>151</sup> Caring activities and hours spent caring were then incorporated into the design of the 1995 survey.

In 1986 Peter Willmott, of the Institute of Community Studies, who had a long-standing interest in community and community care, reviewed informal care surveys, including those of Parker. Willmott suggested that there was still work to be done despite an acknowledgement of informal carers. Highlighting the poorly defined boundary between informal and formal care, Willmott noted:

In one sense the contribution of informal carers is officially recognised, certainly at national level: the policy is based on such a recognition. But there has to be an explicit acknowledgement of its importance at all levels, together with an explicit policy of working with them, supporting them and promoting their participation. Without such a comprehensive recognition there is unlikely to be enough drive to achieve successful care by the community.<sup>152</sup>

Willmott stated that care-giving went beyond that normally expected within families when it became 'arduous or long-standing' and 'the carer or the carers could be regarded as informal substitutes for - or complements to - formal care.'<sup>153</sup> Therefore, social scientists were not only gathering primary data which helped to illuminate the phenomenon of familial caring, but also strived to ensure effectual social policy changes were enacted. In this context, a primary concern was whether community care policies had improved the situation for those with health care needs, including those with mental disabilities, and their carers. Institute for Health

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<sup>151</sup> Ibid., pp. 6-7.

<sup>152</sup> Peter Willmott, *Social Networks Informal Care and Public Policy* (London, 1986), p. 1, p. 115.

<sup>153</sup> Ibid., p. 6.

Policy Studies researcher Angela Spackman noted in 1991 that ‘it is important to recognise that there is no standard definition of “informal carer” and that most studies mean something different by their use of the term.’ Her study considered the health impacts of the caring role on informal carers.<sup>154</sup> Spackman’s report and Willmott’s work, which both commented on the GHS findings, indicate that informal carers had become a research topic in their own right by the start of the 1990s. This more intensive focus on carers allowed researchers to consider the range of carers within the informal carer category, from single women looking after parents to parents bringing up children with disabilities.<sup>155</sup>

That social scientists, including Parker and Willmott, were interested in the issues surrounding so-called informal care demonstrates that the category of the family carer remained contested and contestable throughout the 1980s and the early 1990s. Social scientists, including political scientists and sociologists, intended for their research to lead to political and social changes. The design of social surveys and the questions they asked were constructed not only to report phenomena, but also to allow researchers to interpret and critique social phenomena. The GHS findings encouraged researchers like Parker and Willmott to question what it was to be a carer, how caring should be talked about, and what it involved. Rather than simply providing an evidential base for social policy decisions, the GHS gave social scientists something tangible to hook their analysis on to and helped to ensure that the issue of informal care became and continued to be a highly politicised issue.

The inclusion of carers for relatives with mental disabilities within the GHS survey

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<sup>154</sup> Angela Spackman, *The Health of Informal Carers* (Southampton, 1991), pp. 1-16.

<sup>155</sup> Cherrill Hicks, *Who Cares: Looking After People at Home* (London, 1988); Karl Atkin, ‘Similarities and Differences between Informal Carers’, in Julia Twigg and Karl Atkin (eds), *Carers Perceived: Policy and Practice in Informal Care* (Buckingham, 1994), pp. 30-58.

design ensured that this group, which had previously 'not been included in accounts of care-giving', was considered within social research projects and social policy decisions, focusing national attention on a larger group of informal carers, on a national level.<sup>156</sup> At the same time informal carers began to be conceptualised in their own right rather than exclusively alongside and in relation to the care recipient.

## Conclusions

This chapter has focused on social surveys which were conducted from the late 1950s through to the 1990s by a range of social scientists and others employing social scientific methodologies. During the post-war years social science gained authority and credibility, becoming a key way in which governments and a range of academic disciplines strove to better understand the population and how it could be better managed. This research helped to create and shape a range of phenomena, including the family carer for mental illness and mental handicap. Social surveys, including Enid Mills' *Living with Mental Illness* (1962) and the GHS's *Informal Carers* (1985, 1990, 1995), made the family carer more visible, and an analysis of these surveys and their associated literature can help historians trace the changing place of the carer not only in mental health care, but also in social welfare more broadly. It is significant that the different social scientists who came to research family carers were interested in different research areas and topics.

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<sup>156</sup> Julia Twigg and Karl Atkin, *Carers Perceived: Policy and Practice in Informal Care* (Buckingham, 1994), p. 118.

Mills focused on class and community, whilst Hewett researched disability and familial experience. The SPU became interested in family carers whilst researching the relationship between schizophrenia and social environment. Meanwhile, whilst the GHS demonstrated an interest in mental disability, the primary focus and motivation behind the research was the interplay between community care and an ageing population. What these researchers and research projects had in common was their interest not only in community care, but also relationships and the psychosocial, which led them to examine the family.

From the early post-war years onwards a number of factors, including contemporary concern with family networks, new trajectories within psychiatric research, and new research methodologies, led a generation of researchers employing social scientific methods to focus their attention on the family carer. This focus not only shaped, but in some important respects created the carer as a category. A tendency towards social science methodologies was not the only common denominator between the researchers examined in this chapter; they were all preoccupied, albeit to varying extents, with the notion of community care. This research therefore fuelled, and was fuelled by, contemporary discussions about the nature and feasibility of community care initiatives, many of which focused on whether families could, should, or would provide care for their relatives, couched by contemporaries in terms of duty, obligation and responsibility. The community care debate extended far beyond the role of the carer, allowing researchers like Willmott, with his work on the phenomenon of the carer, to engage with a broader audience. Researchers who focused on community care became interested in the role of the carer in mental health care at the same time as carers

were becoming more visible because of the specific interests of social scientists, whether these were the epidemiology of schizophrenia or demographic changes. By the 1995 GHS, researchers and policy makers had become more interested in the hours spent caring and in the nature of caring activities, and it followed that they would begin to consider the well-being of carers themselves; something which had concerned the ICS and the SPU decades before. In addition, social scientific researchers became interested in the place of both the mentally ill and the mentally handicapped within mental health care, the family, and the community, in the post-war years. The theme of the division between mental illness and mental handicap will be returned to throughout this thesis and discussed in detail in Chapter Six.

Social science research in the post-war period not only brought mental illness and mental handicap in the family into view, it also contributed to the creation and shaping of the family carer as a category. By the 1990s, social researchers attempting to count the number of carers in Britain had begun to deconstruct the category of carer to differentiate, for example, between carers for mental illness and the elderly, and had also provided a mechanism through which family members providing care for relatives could identify themselves as carers. This also ensured the family carer continued to be a contested and contestable category. In this way, and in light of the social policy influence of researchers, social scientists both created and shaped the category, and the actuality, of the family carer in post-war England and Wales.



# 3.

## **Television and Film Representations of the Family Carer, c. 1960-1999**

As the post-war years progressed there was a growing public awareness of the place of the family carer in mental health care that was, in part, facilitated by film and television representations. During the 1960s, documentaries commissioned by parent groups offered insight into the role of parents in the care of their mentally handicapped children. However, the role of the family in the care of people with mental illness was rarely reflected in television portrayals at this time. By the mid-1990s the role of the family was more apparent with carers for people with both mental illnesses and learning disabilities appearing as talking heads in television documentaries. This move towards broader awareness coincided with developments in the social policy and social research arenas where the place of the family carer in mental health care had also come into clearer view by the close of the twentieth century. Documentaries from the mid-1990s also demonstrated a growing critical awareness from relatives who explained their experiences on screen, and some of whom were seen actively resisted their categorisation as

carers. The focus of this chapter is on television and film representations of the family carer, with an emphasis on the ways in which relationships were explored and portrayed via the media of documentaries and documentary-dramas.

Historians have tended to overlook television, film, and indeed broader media representations of family carers in the post-war period. However, by the mid-1960s television had become an important part of family life in the home.<sup>1</sup>

There is a growing scholarship focusing on media representations of mental illness in this period, which is part of a broader historiography of public representations of mental illness.<sup>2</sup> Scholars have analysed whether television and film representations of the mentally ill contributed to the stigmatisation of the mentally ill, with media representations exhibiting a tendency towards entertaining rather than educating the public.<sup>3</sup> Sociologist Greg Philo and the Glasgow Media Group have interrogated whether the media had a positive impact on understandings of mental illness and have also thought about the ways in which family carers were incorporated in and affected by these representations.<sup>4</sup> Historian Vicky Long has examined television representations of the mentally ill and the impact this had on destigmatisation.<sup>5</sup>

As the influence of and accessibility to television grew in the post-war years so too did the amount of programming on mental illness and learning disability,

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<sup>1</sup> John Newson and Elizabeth Newson, *Four Years Old in an Urban Community* (London, 1968), p. 34; David Oswell, *Television, Childhood, and the Home: A History of the Making of Child Television Audiences in Britain* (Oxford, 2002), pp. 87-89; Mathew Thomson, *Lost Freedom: The Landscape of the Child and the British Post-War Settlement* (Oxford, 2013), pp. 112-13.

<sup>2</sup> Sander L. Gilman, *Seeing the Insane* (London, 1996).

<sup>3</sup> Greg Philo, 'Users of Services, Carers and Families', in Greg Philo (ed.), *Media and Mental Distress* (London, 1996), pp. 105-18.

<sup>4</sup> Philo, *Media*; Greg Philo (ed.), *Message Received: Glasgow Media Group Research, 1993-1998* (Harlow, 1998).

<sup>5</sup> Vicky Long, 'Changing Public Representations of Mental Illness in Britain 1870-1970' (PhD thesis, University of Warwick, 2004); Vicky Long, *Destigmatising Mental Illness: Professional Politics, Stigma, and Public Education in Britain, 1870-1970* (Manchester, forthcoming).

facilitated by the process of deinstitutionalisation and the rise of the service-user and self-advocacy movements. Regardless of whether these programmes had a positive or negative impact on attitudes towards mental health, film and television portrayals acted as a site and trigger of discussion and debate, contributing to the emergence and negotiation of the category of the family carer.

Following the Second World War there was a move away from a purely interior view of psychiatry and psychology, towards an approach which considered external factors, and in particular social environment.<sup>6</sup> An interest in the psychosocial lent itself particularly well to the media of film and television because of their focus on relationships, dialogue, and the emotions. As historian Thomas Dixon has argued, the emotions emerged as a psychological category in the modern period.<sup>7</sup> With the growing popularity of psychology as a discipline in the post-war period came an interest in emotional understandings of the self and inter-personal relationships, in terms of both restraint and control, and love and nurture.<sup>8</sup> Indeed, among various interested parties including those associated with anti-psychiatry, child guidance experts, and social psychiatrists, there was a growing focus on attempts to get people to express their emotions in healthy and productive ways.

With deinstitutionalisation the family and the family home became increasingly important as social relationships and social environments which had the capacity to be viewed as both pathological and therapeutic. The family, or more

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<sup>6</sup> See Chapter Two of this thesis for an examination of psychological and psychosocial research into the environment of the family home.

<sup>7</sup> Thomas Dixon, *From Passions to Emotions: The Creation of a Secular Psychological Category* (Cambridge, 2006), p. 1.

<sup>8</sup> Deborah Cohen, *Family Secrets: The Things We Tried to Hide* (London, 2014), pp. 212-40; Barbara H. Rosenwein, 'Worrying about Emotions in History', *American Historical Review*, 107:3 (2005), p. 827.

specifically parents, were considered by some to be key to child development, whilst others saw the family as either a causal factor in mental illness, or the solution when in receipt of therapy. All of these roles and functions could be effectively depicted on screen where dialogue, body language, and heightened emotion could be captured. Indeed, as Thomas Dixon has argued, the space of the family home, and in particular the living room, is an example of a space where 'emotions have been brought into existence by the enactment of communal narratives, visual representations, medical theories, and moral codes.'<sup>9</sup> Barbara E. Rosenwein has helpfully proposed that researchers looking at social communities, including families, often attempt to 'uncover systems of feeling' within these "'emotional communities'".<sup>10</sup> Documentary-drama offers an ideal conduit to represent and explore this preoccupation with trying to better understand emotions and relationships within communities.

This chapter considers three key periods in screen representations of the place of the family carer in mental health care. Firstly, I examine the short documentary films produced during the 1960s by Derrick Knight & Partners and commissioned by parent and carer groups to educate the public about severe handicaps. The films I discuss are: *One of the Family* (1964), *One of them was Brett* (1965), *Stress: Parents with a Handicapped Child* (1966), *A Place like Home* (1969), and *New Way at Northgate* (1969). Many documentaries and films portraying mental handicaps were made during, and indeed before, the early 1960s. Whilst many of these films paid little or no attention to the relatives of the patient, the

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<sup>9</sup> Thomas Dixon, 'History in British Tears: Some Reflections on the Anatomy of Modern Emotions', *A Lecture Delivered at the Annual Conference of the Netherlands Historical Society* (4 November 2011), p. 3.

<sup>10</sup> Rosenwein, 'Worrying', p. 842.

films produced by DKP considered the impact of mental handicap on the rest of the family. These documentaries incorporated interviews with parents and, in particular, mothers allowing a view into the personal experiences of families. I argue that similar films about the role of families in the care of the mentally ill did not emerge until later. Secondly, I examine the portrayal of family members of those suffering from schizophrenia during the late 1960s and 1970s in Ken Loach's *In Two Minds* (1967) and *Family Life* (1971). During this decade the family often functioned as a battleground for the contestation of the preferred explanations for the causes of and treatments for schizophrenia, which lent itself to visual representation. Whilst anti-psychiatry and its followers within the broader counter-culture viewed the family as the cause of and the solution to mental illness, others, including carers themselves, fought to challenge this view. This, I argue, made the public, and carers, familiar with the notion that mental illness was as much a concern of family groups as of individuals and thus laid the ground for the subsequent acknowledgement of the carer role.

Thirdly, I examine three programmes aired on Channel 4: *Walter* (1982), *Edge of Madness* (1996), and *Access All Areas: Down's Syndrome* (1999). I argue that film and television portrayals of family carers became more widespread during the 1980s and 1990s as the role of the carer became increasingly acknowledged, and as Channel 4 attempted to destigmatise and educate about mental illnesses and disabilities. Further, I argue that the language used by carers who appeared in documentaries as talking heads during the 1990s demonstrates that relatives of those with mental handicaps and mental illnesses were not only aware of their

designation as carers by this point in the time, but that they were willing to negotiate, challenge, or reject this designation.

I argue, then, that the public view of the place of the family carer in mental health care became increasingly multi-faceted as the twentieth century progressed. Television and film acted as a site where the complications and contradictions arising from the emerging category of the carer could be conveyed to a broader public. Film-makers increasingly entered the family home. They portrayed it as a site that could provoke illness and relapse, but that could also foster care, rehabilitation, and therapy.

### **Parent Groups and Documentary Film, c. 1960-69**

Small British production company, Derrick Knight & Partners (DKP) was set up in 1957.<sup>11</sup> Knight directed public information films, including the government's Central Office of Information-commissioned *Smoking and You* (1963). This activity created a reputation that attracted commissions from parent and carer groups for people with mental and physical handicap. Subsequently, DKP produced documentaries for parent groups throughout the 1960s.<sup>12</sup>

DKP produced two films for the National Spastics Society (NSS), *One of the Family* (1964) and *A Place Like Home* (1966). The interaction between the NSS, incepted in 1952, and the media was not new. The NSS were keen to raise cerebral

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<sup>11</sup> For more on Derrick Knight and Derrick Knight & Partners see Bert Hogenkamp, 'Between Two Worlds: Derrick Knight', in Patrick Russell and James Piers Taylor (eds), *Shadows of Progress: Documentary Film in Post-War Britain* (Basingstoke, 2010), pp. 389-405.

<sup>12</sup> Hogenkamp, 'Knight', pp. 396-97.

palsy awareness, and to educate parents, medical professionals, parliament, and the public. The Society published leaflets, content for the press, newsreels, and a newsletter, *Spastics News*, which enabled parents to communicate with one another. This connection with the press was established early in the charity's history with a letter published in the *Daily Mirror's* Live Letters section in 1951 written by the first Chairman of the Society, Ian Dawson Shepherd, attracting 300 replies.<sup>13</sup> In 1952 the *Daily Mirror's* Ruggles cartoon - which depicted 'A fictitious suburban couple interested in social issues' - featured a 'spastic' child for six days.<sup>14</sup> The Ruggles cartoons were sympathetic to the work of the NSS and discussed the need for parent groups, early treatment, and special education, along with the Society's aims and the above-average intelligence of many 'spastic' children.<sup>15</sup>

The NSS used pubs and shops as funding centres and involved celebrities in their campaigning efforts, including entertainers Wilfred Pickles and Australian-born Bill Hargreaves. Hargreaves was born with cerebral palsy. His father was told by a doctor that Bill would 'never walk, work or wed'. However, after attending school and moving to England Hargreaves began to work, first in his father's soap factory and later as an entertainer. Hargreaves recalled 'there weren't any people with cerebral palsy in the streets at all . . . Why? Because their parents were ashamed of having their children seen'. He became involved in the NSS as the first executive committee member with cerebral palsy, as chairman of the Corby group, and as industrial liaison officer from 1957. He helped people with cerebral palsy get

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<sup>13</sup> Chris Davies, *Changing Society: A Personal History of Scope (formerly The Spastics Society) 1952-2002* (London, 2002), p. 23.

<sup>14</sup> For copies of these cartoon strips see: Davies, *Changing*, pp. 30-31.

<sup>15</sup> Davies, *Changing*, pp. 30-31, 35.

jobs and set-up self-help groups, including sixty-two clubs, run by people with cerebral palsy.<sup>16</sup>

The NSS's first film to appear on television, *Every Eight Hours* (1960), was not produced by DKP.<sup>17</sup> The film, and the book version (1964), were written and narrated by broadcaster Richard Dimbleby, a familiar face on BBC television, having broadcast during the Coronation and the Second World War, and as the presenter of *Panorama* since 1955. *Every Eight Hours* was regularly on national television and told the story of the Spastics Society. Dimbleby explained what cerebral palsy was and the services set up by the NSS, including schools, and called for more research. Whilst families were only briefly mentioned in the *Every Eight Hours*, it was noted that the 1960 estimate of 40,000 'spastics' in Britain was likely to be an underestimate, because many children were hidden away by families. Acknowledging a longer history of services for those with handicaps, Dimbleby posited that the advent of the National Health Service actually meant that less money was spent on services for these individuals as money was directed elsewhere. As argued throughout this thesis, at times of service restructuring, especially in terms of deinstitutionalisation, there tended to be a focus on the family as a locus of care. Dimbleby asserted that parents wanted help for their children, particularly because delayed treatment was thought to lead to more problems for 'spastic' children.

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<sup>16</sup> Alex White, 'Hargreaves, William Mason Creer (1919–2000)', *Oxford Dictionary of National Biography*, (Oxford, October 2007).

<sup>17</sup> *Every Eight Hours*, dir. by Phil Wrestler (Libertas Films, 1960).



The Spastics Society, then, had campaigned via the media for over a decade when the DKP documentary short, *One of the Family* (1964), was released.<sup>18</sup> The documentary, intended for a general audience, was distributed jointly by the NSS and (as with all DKP films on health topics) Concord Media, a small company established in 1959. Free copies of *One of the Family* were loaned to groups including film societies, women's organisations, and youth clubs.<sup>19</sup> The documentary was written and directed by documentary film-maker Bernice Rubens who had a particular interest in families. Rubens intended to 'illustrate real-life living'.<sup>20</sup> Before becoming a film maker Bernice Rubens was an English teacher and she later became a successful novelist, with many of her novels centred on the theme of the family. Rubens was also friends with David Mercer, screenplay writer for *In Two Minds* (1957), which was directed by Ken Loach and is discussed in the next section of this chapter.

*One of the Family* focused on relatives caring for children with cerebral palsy at home and showed some of the services made available to them by the NSS. The film showed medical professionals working at the Spastic Society's headquarters in Nottingham, assessing children with cerebral palsy, and a home visitor at work. Later, the film focused on the Family Help Unit in Nottingham, a residential facility intended to provide periods of respite to parents ranging from one day to a few weeks.<sup>21</sup>

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<sup>18</sup> *One of the Family*, dir. Bernice Rubens (Derrick Knight and Partners, 1964); Hogenkamp, 'Knight', p. 397.

<sup>19</sup> *Film User* (July 1989), p. 22.

<sup>20</sup> *Film User* (July 1989), p. 22; Bernice Rubens, *When I Grow Up: A Memoir* (London, 2005), p. 114; Janet Watt, 'Obituary: Bernice Rubens', *Guardian*, 14 October 2004.

<sup>21</sup> Sheila Hewett, *The Family and the Handicapped Child: A Study of Cerebral Palsied Children* (London, 1970), p. 15. This study is discussed in detail in Chapter Two of this thesis.

*One of the Family* portrayed the parents of children with cerebral palsy in a number of ways. When the doctors discussed a child after an assessment one doctor said 'I think the parents will be a little disappointed by this', to which another added 'yes, they had high expectations for her'. There is a sense that some parents struggled to come to terms with their child's illness, with some experiencing feelings of pity and guilt. Parents, and in particular mothers, are presented as having to provide care for their child. Indeed, the narrator explained, 'day after day, often without sleep, they are tied to their handicapped children'. The narrator stated that the NSS worked to ensure children were not confined either in institutions or the family home, and had set up The Mount, a temporary residential home in Nottingham, to provide respite care for the children so their parents could have a break.

Whilst the documentary illustrated that parents could often understand their children better than anyone else, there was a clear message that all families were different. There was also an emphasis on the external assistance that was available. Parents were portrayed confiding in social workers and a home visitor, asking questions about their child's care. The home visitor, Mrs Marsh, noted: 'There are some parents who won't accept help of any kind. They are too proud and they'd sooner go without. It's silly really, anyone would think it was their fault they had a spastic child. Most families are glad to see me though.' Historian Pamela Dale has argued that once health visitors in this period identified a disabled child, medical intervention into, and training of, the family often followed.<sup>22</sup> The film provides evidence to support this argument, but also suggests that some families

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<sup>22</sup> Pamela Dale, 'Health Visiting and Disability Issues in England before 1948', in Anne Borsay and Pamela Dale (eds), *Disabled Children: Contested Caring, 1850-1979* (London, 2012), pp. 128-29.

resisted this medical intervention. Parents were not directly interviewed within the film, but they were included in the narrative and importantly shown, not as a cohesive group, but as having individualised responses to their child's condition and with particular support requirements. In *One of the Family* parents were shown discussing their needs, issues, and problems with medical professionals working with the NSS. Rather than the care of mentally handicapped children being provided by trained professionals, parents are represented as taking an active role in their child's care and the hardships faced by these parents are discussed.

In 1969 DKP released another NSS-commissioned documentary, *A Place Like Home*.<sup>23</sup> Narrated by actor Brian Rix, the documentary compared the experiences of children living in a purpose-built hostel with those living in a large institution. Rix, who had a daughter and grandson with Down's Syndrome, later became heavily involved in Mencap. He became Mencap secretary-general in 1980, chairman in 1987, and president in 2002. The film emphasised the advantages of the hostel environment for children with cerebral palsy, but did not make clear distinctions between these and more traditional, large institutions. However, the documentary keenly stressed that the family home was the ideal environment for the care of all children, including those with cerebral palsy:

A subnormal child can be born into any family, even the most normal and healthy and irrespective of social class. If society were . . . more willing to support families who have a subnormal member, more of these children might be able to live in their own homes.

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<sup>23</sup> *A Place Like Home*, Dir. Peter Neal (Knight Film Productions, 1970).

Whilst the documentary did not directly show instances of families providing care for children with cerebral palsy, the voice-over repeatedly states that this would be the ideal situation. This fits with broader concerns at the time for children, including those with physical and mental handicaps, to stay with their families and be brought up by their parents.

Similar to *A Place Like Home* was the DKP film *New Ways at Northgate* (1969), directed by David Gladwell and commissioned by the National Society for Mentally Handicapped Children (NSMHC).<sup>24</sup> The documentary focused on the closure of long-stay institutions, and examined the move by Northgate hospital for the mentally subnormal in Northumberland to provide intensive short-term treatment as opposed to long-stay residential care. The film also focuses on family members, with Dr Peter Sykes speaking with parents.

In 1965 DKP released *One of Them was Brett*, commissioned by The National Society for the Aid of Thalidomide Children (NSATC).<sup>25</sup> In the film, which went on to 'have a very successful television career', the parents of four-year-old Brett Nielson, a child born with deformities caused by the drug thalidomide, are shown caring for their son and arranging for him to have artificial limbs fitted.<sup>26</sup> Brett's mother is given a voice in the film. She describes her feelings of resentment and guilt because Brett required more help than her other children, until she realised that Brett was crying for more independence. She described the difficulties she had faced with members of the public confronting her assuming that Brett's

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<sup>24</sup> *New Ways at Northgate*, Dir. David Gladwell (Knight Film Productions, 1969).

<sup>25</sup> *One of Them was Brett*, Dir. Roger Graef (Derrick Knight & Partners, 1965).

<sup>26</sup> Hogenkamp, 'Knight', p. 397. Brett was born in Australia and his family moved to London for his father's work.

deformities had resulted from her taking narcotic drugs. The narrator of the documentary, actor Stanley Baxter, explained that Brett's family faced a handicap itself, self-pity. The film suggested that self-pity would be alleviated once Brett was fitted with motor-powered artificial limbs. The driving message of the film is that, rather than dwelling on their hardships, Brett's family and the medical profession, should focus on helping them 'to unlock the chains of dependence that bind their future'. The message of *One of the Them is Brett* was that the care provided by relatives of thalidomide children could be helped by the encouragement of social acceptance and the intervention of the medical profession via artificial limbs.

In 1966 DKP released *Stress: Parents with a Handicapped Child* a documentary sponsored by the Mental Health Film Council, founded in 1963 as part of the Mind Campaign of the National Association of Mental Health.<sup>27</sup> *Stress* was distributed by Concord, the NSS, and the NSMHC. It was also shown on the BBC, and within two years the initial print-run of twenty-five reels was increased to seventy copies in the UK, with additional prints distributed worldwide.<sup>28</sup> The film, directed by Bernice Rubens and narrated by actor and politician Andrew Faulds, explored the ways stress affected families caring for mentally handicapped children. The documentary was part of a broader context in which academics, medical professionals, and social workers were becoming more concerned about the impact of stress on health and well-being.<sup>29</sup> As historian Mark Jackson has argued, once

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<sup>27</sup> *Stress: Parents with a Handicapped Child*, Dir. Bernice Rubens (Derrick Knight & Partners, 1966).

<sup>28</sup> Bernice Rubens, 'Face to Face with Stress', *Film User Supplement: Knight Films: The First Ten Years: A Progress Report* (1968), pp. xi-xii; Derrick Knight, 'Who is it all for?', *Film User Supplement: Knight Films: The First Ten Years: A Progress Report* (1968), p. xix.

<sup>29</sup> Mark Jackson, *The Age of Stress: Science and the Search for Stability* (Oxford, 2013), p. 3, pp. 10-11, pp. 15-16. See also, Chapter Two of this thesis for more on the contemporary concern over stress.

stress could be quantified, contemporaries were able to employ it as an 'indicator and determinant of individual and social pathology.'<sup>30</sup> Thus, stress could be used by experts to measure the success of policies like community care and subsequently as a means to improve the quality of life of those at risk of suffering from stress.

Rather than homogenising the nature of stress experienced by families with mentally handicapped children, Rubens aimed to highlight the diversity of experience:

It became apparent that stress was due in varying degrees to different causes.

There was the pure emotional stress caused by having produced a handicapped child, with the subsequent strain on the marriage and the other children. There was stress due to financial hardship and problems of accommodation; the stress of sheer physical exhaustion and the stress that was the result of public indifference and inadequate services.

Explaining that her brief was 'like being asked to go through a stranger's pockets or to read somebody's diary', Rubens was concerned about the potential stress caused by the participants' involvement in the documentary-making process.<sup>31</sup> In 1968

Rubens noted: 'There are moments in such filming when you have to decide to go on shooting or whether a film, however good, is worth the distress it causes'.<sup>32</sup>

Perhaps to address this issue, *Stress* was shown to the five families featured in the documentary before its release. According to media historian Bert Hogenkamp, 'this [preview] led each of them to conclude that other families were worse off than

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<sup>30</sup> Jackson, *Stress*, pp. 10-11.

<sup>31</sup> Rubens, 'Stress', pp. xi.

<sup>32</sup> *Ibid.*, pp. xi-xii.

themselves.<sup>33</sup> Thus, the film encouraged families to think reflexively about their experiences of caring in relation to others in a similar, yet different, position. In turn, caring relatives viewing the final documentary may have constructed their own narrative as a parent of a handicapped child in new ways because they had heard others articulate their experiences in a particular way.<sup>34</sup>

In contrast to the numerous television programmes produced on the topic of mental handicap before the 1960s, there were fewer film and television representations of mental illness, and in particular, hardly any evidence of family care-givers for the mentally ill. However, historian Vicky Long has analysed the 1956 BBC documentary series on mental health, *The Hurt Mind*. Yet, aside from the letters that friends and relatives wrote into the BBC following the television broadcasts, Long's analysis does not include reference to the relatives of the mentally ill.<sup>35</sup> Whilst television and film representations of mental health and mental illness require further study for the early post-war period, many documentaries and films from this period did not consider the role of the family in care to any great extent.

An example of a film portrayal of mental illness in the early post-years, however, is *The Snake Pit* (1948). Adapted from Mary Jane Ward's autobiography, the film told the story of Virginia a woman being poorly treatment once admitted to an American mental institution.<sup>36</sup> Although seeming to fit into the category of melodrama, the film was highly controversial upon its release, especially 'because

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<sup>33</sup> Hogenkamp, 'Knight', p. 398.

<sup>34</sup> Deborah Lupton, *The Emotional Self: A Sociocultural Exploration* (London, 1998), pp. 18-19, pp. 170-71.

<sup>35</sup> Vicky Long, *Destabilising Mental Illness: Professional Politics, Stigma, and Public Education in Britain, 1870-1970* (Manchester, forthcoming), pp. 291-329.

<sup>36</sup> *The Snake Pit*, Dir. Anatole Litvak (Studiocanal, 2004).

many thought they were witnessing a documentary, or dramatized-documentary', owing to the new techniques adopted by the Hollywood film makers.<sup>37</sup> Whilst the film was banned in some British counties, a large number of Britons will have still seen the film upon its release, with an average of 30 million Britons visiting the cinema each week.<sup>38</sup> Psychoanalyst Dr Kik was portrayed positively in the film, helping to improve Virginia's illness, in part by exploring family issues she had in her childhood.<sup>39</sup> Whilst Virginia's family only appear in a flashback, her husband is given more of a role seeking her discharge and telling Virginia, 'it's just like any other illness, dear'.

Similarly to *The Snake Pit*, the British Medical Association's *And Then There Was One* (1967) gave a marginal role to the family of the patient. Aimed at a professional audience, the film followed four people with depression and indicated that families often struggled to understand those with depression, instead perceiving them as a burden. This is in contrast to the narrative of DKP films which championed the therapeutic and developmental benefits of families.

In summary, during the 1960s the small production company DKP released films which increased awareness of various mental and physical handicaps which affected both children and their parents. Although parents were not always the central focus of these documentaries, they, and in particular mothers, are shown adopting a caring role in their child's life and needing support services and training from the medical profession. The films indicated that the family environment could be an ideal locus of care for handicapped children, but that families required both

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<sup>37</sup> Michael Shortland, 'Screen Memories: Towards a History of Psychiatry and Psychoanalysis in the Movies', *British Journal for the History of Science*, 20: 4 (October 1987), p. 424.

<sup>38</sup> Ibid., p. 426.

<sup>39</sup> Ibid., p. 430.



social and medical support to be effective care-givers. The films were part of a move by national charities to educate the public about mental handicap during the 1960s, with an emphasis on the importance of the role of the family in care. However, the DKP films were by and large produced to promote specific organisations and therefore are unlikely to give a rounded view of the day-to-day experiences of all carers. Even so, family care-givers for mental and physical handicap were represented on-screen long before those for mental illness, with the relatives of those with mental illnesses missing from the screen in the 1950s.

### **Documentary-drama and Anti-Psychiatry, c. 1964-1972**

During the 1960s and 1970s ideas associated with anti-psychiatry percolated throughout society via the press, broadcasting, paperback books, film, and television. Indeed, two documentary-dramas directed by Ken Loach *In Two Minds* (1967), part of the British Broadcasting Corporation's (BBC) *The Wednesday Play* series, and the subsequent film version *Family Life* (1971), drew upon the work of David Cooper and R.D. Laing who were associated with the anti-psychiatry movement.<sup>40</sup>

Anti-psychiatry came to be seen as a critique of traditional, institutional psychiatry, presenting a range of challenges to traditional psychiatry, including critiques of medical interventions such as electroconvulsive therapy (ECT) and calls for the closure of long-stay institutions. Although the phrase 'anti-psychiatry'

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<sup>40</sup> *In Two Minds*, Dir. Ken Loach (BBC, 1967); *Family Life*, Dir. Ken Loach (Studiocanal, 2007). *Family Life* was released as *Wednesday's Child* in the United States of America.

became popular during the 1960s and 1970s those associated with the so-called movement held a range of views and did not perceive themselves to be part of a distinct group. As British psychiatrist Digby Tantam has stated, they had 'no manifesto'.<sup>41</sup> Erving Goffman and Michel Foucault were critical of mental hospitals, viewing institutional psychiatry as a form of social control, whilst Thomas Szasz argued that mental illness was nothing more than a socially constructed label. Indeed, anti-psychiatry has also been described as a 'kaleidoscope' that did not, in reality, constitute a cohesive movement.<sup>42</sup> David Cooper coined the phrase anti-psychiatry in 1967 but many of the key figures that came to be associated with the so-called movement, including Michel Foucault and Thomas Szasz, rejected the term.

Some of the trained psychiatrists linked to the so-called anti-psychiatry movement, particularly R.D. Laing and David Cooper, argued that the family and home environment, along with wider society, had a pathological effect on the young people who came to be diagnosed, or labelled, as schizophrenic.<sup>43</sup> Initially, Laing focused on the schizophrenogenic capacity of mothers who, by obstructing their child's development of a sense of self, he believed, caused them to become

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<sup>41</sup> Digby Tantam, 'The Anti-Psychiatry Movement', in Hugh Freeman and German Berrios (eds), *150 Years of Psychiatry: The Aftermath* (London, 1996), p. 334.

<sup>42</sup> Marijke Gijswijt-Hofstra, 'Introduction: Cultures of Psychiatry and Mental Health in Postwar Britain and the Netherlands', in Marijke Gijswijt-Hofstra and Roy Porter (eds), *Cultures of Psychiatry and Mental Health Care in Postwar Britain and The Netherlands* (Amsterdam, 1998), p. 2.

<sup>43</sup> For an examination of David Cooper and R.D. Laing's theories on the family see: Deborah Cohen, *Family Secrets: Living with Shame from the Victorians to the Present Day* (London, 2013), pp. 212-40. For the early work of R.D. Laing, see: Allan Beveridge, *Portrait of the Psychiatrist as a Young Man: The Early Writings and Work of R.D. Laing, 1927-1960* (Oxford, 2011). For a feminist critique of R.D. Laing, see: Elaine Showalter, *The Female Malady: Women, Madness and English Culture, 1830-1980* (2nd edn, London, 1987), pp. 220-47.

fragmented and seemingly ill.<sup>44</sup> Laing explained the term 'schizophrenogenic' via the following description:

there may be ways of being a mother that impede rather than facilitate or "reinforce" any genetically determined in born tendency there may be in the child towards achieving the primary development stages of ontological security.

Laing later broadened this idea to consider 'schizophrenogenic families' and he subsequently recommended the use of family therapy sessions as a form of schizophrenia treatment.<sup>45</sup>

Psychiatrist and historian Trevor Turner has explained that a range of orthodoxies had become established in the field of psychiatry by the 1970s, but opinion over schizophrenia remained particularly divided.<sup>46</sup> Schizophrenia had no clear aetiology and often presented itself during adolescence. A chronic condition with acute phases, schizophrenia had varying degrees of severity and had a long-standing association with the family.<sup>47</sup> Many of the long-stay patients discharged from mental hospitals as part of the deinstitutionalisation process had diagnoses of schizophrenia. There was widespread concern that local communities were ill-equipped to care for these individuals and that drug therapies alone would not be enough, especially because of the risk-factors associated with the condition. Such

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<sup>44</sup> R.D. Laing, *The Divided Self: An Existential Study in Sanity and Madness* (Harmondsworth, 1965), p. 205.

<sup>45</sup> Laing, *The Divided Self*, p. 206. See also, David Cooper, *The Death of the Family* (London, 1971), p. 29.

<sup>46</sup> Trevor Turner, 'Schizophrenia: Social Section', in German Berrios and Roy Porter (eds), *A Clinical History of Psychiatry* (London and New York, 1995), pp. 350-51.

<sup>47</sup> Roy Porter, 'Anti-Psychiatry and the Family: Taking the Long View', in Marijke Gijswijt-Hofstra and Roy Porter (eds), *Cultures of Psychiatry and Mental Health Care in Postwar Britain and The Netherlands* (Amsterdam, 1998), p. 257-70.

concern encouraged new research on the illness. Traditional, institutional psychiatry took a biomedical view of schizophrenia, concentrating on the use of psychotropic drug therapies and finding a cure for the condition.<sup>48</sup> Concurrently, social psychiatrists and non-medical psychiatric professionals, including social workers, predominantly subscribed to a social model of mental illness that focused on the patient's environment and the social aspects of their condition.<sup>49</sup>

Some historians have argued that those associated with anti-psychiatry were often marginalised within these debates. Indeed, historian Colin Jones has argued that writers associated with anti-psychiatry tended to be underrepresented within academic journals, such as the *Bulletin of Schizophrenia* and the *British Medical Journal*, during the 1970s.<sup>50</sup> Despite this, figures associated with anti-psychiatry, including R.D. Laing, became associated with the broader counter-culture of the 1970s, and views associated with other anti-psychiatry figures, became popularised by the media.

On 1 March 1967 *The Wednesday Play*, *In Two Minds*, produced by Tony Garnett and written by David Mercer, aired on the BBC for the first time. The play was directed by Ken Loach who only became involved with *In Two Minds* part-way through the project.<sup>51</sup> *The Wednesday Play* series aired on BBC television between 1964 and 1970, with the documentary-dramas aiming not only to engage with

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<sup>48</sup> Peter Barham, *Closing the Asylum: The Mental Patient in Modern Society* (London, 1992), p. 14.

<sup>49</sup> Lucy Johnstone, *Users and Abusers of Psychiatry: A Critical Look at Traditional Psychiatric Practice* (London, 1989), p. 83; Porter, 'Anti-Psychiatry', p. 257. For more on the medical (physical) and social understandings of mental illness see: Vicky Long, "'Often there is a Good Deal to be Done, But Socially Rather Than Medically'" The Psychiatric Social Worker as Social Therapist, 1945-70', *Medical History*, 55 (2011), pp. 233-37.

<sup>50</sup> Colin Jones, 'Raising the Anti: Jan Foudraïne, Ronald Laing and Anti-Psychiatry', in Marijke Gijswijt-Hofstra and Roy Porter (eds), *Cultures of Psychiatry and Mental Health Care in Postwar Britain and The Netherlands* (Amsterdam, 1998), p. 288.

<sup>51</sup> John Hill, *Ken Loach: The Politics of Film and Television* (London, 2011), p. 4.

social issues, from apartheid to homelessness, but also seeking to influence public opinion. *The Wednesday Play* was part of a broader trend of real-life, or kitchen sink, dramas about ordinary people which continued into the 1970s.<sup>52</sup> Using techniques from documentary film making, *In Two Minds* told the story of Kate Winter, a young woman diagnosed with schizophrenia. The film explored her family life and her experiences of institutional care. As Kate's condition deteriorates during the film, the script is increasingly critical of Kate's family and the staff at the hospital where she is admitted. Throughout the play Kate's parents seem to want to help, but are seen to clash with Kate over issues including her boyfriend and her mother's insistence that she have an abortion when she discovers her pregnancy. During one of these clashes Kate's mother says 'you're no better than a prostitute . . . I hardly recognise you sometimes'. Her father seems to support the medical model of mental illness stating 'it's as though you've got a broken arm.' Kate's sister Mary tries to encourage Kate to move in with her but Kate is unwilling to leave her parents, which supports the idea, derived from anti-psychiatry, that her family are schizophrenogenic and 'suffocating' Kate.

Although Kate lives with her parents and they are seen to support her, to a limited degree, her parents are not portrayed as providing care as such. Kate's parents spend time with her, visit her in hospital, and talk to her about her 'problems', but they do not seem to provide the thirty-five hours of care per week required to qualify for Invalid Care Allowance. However, according to the NSF's definition, a caring relative 'means the close relative or family member who would normally and willingly offer a home to the mentally sick relative on discharge from

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<sup>52</sup> Laurel Forster, '1970s Television: A Self-conscious Decade', in Sue Harper and Justin Smith (eds), *British Film Culture in the 1970s: The Boundaries of Pleasure* (Edinburgh, 2012), p. 96.

Hospital', whereas a concerned relative 'means the relative whom, in the temporary or permanent absence of a caring relative, the patient would usually turn for advice'.<sup>53</sup> According to this definition, Kate's parents were caring relatives, if not 'carers'.

The closing scene showed a doctor explaining Kate's diagnosis to a room full of trainee doctors with a heavy emphasis on the medical model. The doctor explains: 'Family history is negative and there's no detectable relationship between her various symptoms and her environment.' He goes on to discuss various physical treatment options from electroconvulsive therapy to brain operations. Various trainee doctors are then seen questioning and challenging this prognosis using information and detail included earlier on in the film. The final words of the play is dedicated to the most detailed of these challenges:

With due respect Sir you seem to be studiously avoiding any environmental factors. You seemed to have a lot of them brought up. Strained relationships with her mother, associating with undesirable friends, her sister leaving home and so on and you seem to be assiduously avoiding this and saying the disease is something almost by itself. Surely both before as a cause of her illness and after as a means of treatment one's got to take in account her home background.

In this scene the questions posed by the trainee doctors appear closely connected with the views of R.D. Laing. Whilst Mercer initially argued that his script was not based on the views of any particular school of psychiatric thought, it later became

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<sup>53</sup> WL, PP/DSI/C/1/9, *Good Relations: A Code of Practice for those Discharging Patients* (1983), p. 3.

common knowledge that the play's script was in fact inspired by R.D. Laing and Aaron Esterson's *Sanity, Madness and the Family* and that Laing himself, along with David Cooper, had acted as expert advisors on the production.<sup>54</sup>

In *Sanity, Madness and the Family* Laing and Esterson aimed to 'show that the experience and behaviour of schizophrenics is much more socially intelligible than has come to be supposed by most psychiatrists.'<sup>55</sup> Rather than the individual being ill and in need of treatment, they asserted that 'not the individual but the family is the unit of illness: not the individual but the family, therefore, needs the clinician's services to cure it'.<sup>56</sup> In 1971 Cooper also wrote about the pathogenic capacity of the family in his book *The Death of the Family*: 'The family, since it cannot bear doubt about itself and its capacity to engender "mental health" and "correct attitudes", destroys doubt as a possibility in each of its members.'<sup>57</sup> In *Two Minds* is explicit in its assertion that the family have a pathogenic effect on those who become diagnosed with schizophrenia, a position with political resonance at the time. As media studies academic John Hill has asserted, Loach tended to 'draw attention in his films to the shortcomings of contemporary economic and social arrangements while maintaining the possibility that there might be political alternatives.'<sup>58</sup> That *The Wednesday Play* presented evidence to discount Kate's diagnosis of schizophrenia is therefore unsurprising given Laing's view expressed in

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<sup>54</sup> *Sanity, Madness and the Family* was initially published by Tavistock Press. A Pelican paperback version of the book was published in 1970 (Pelican, a division of Penguin Books, published books intended to educate rather than just entertain the public). R.D. Laing and A. Esterson, *Sanity, Madness and the Family* (London, 1964); R.D. Laing and A. Esterson, *Sanity, Madness and the Family* (2nd edn, Harmondsworth, 1970).

<sup>55</sup> Laing and Esterson, *Sanity*, p. 27.

<sup>56</sup> Ibid., p. 22.

<sup>57</sup> Cooper, *The Death*, p. 9.

<sup>58</sup> Hill, *Loach*, p. 1.

1964 that 'I do not myself believe there is any such "condition" as "schizophrenia".

Yet the label is a social fact. Indeed this label as social fact, is a *political event*.<sup>59</sup>

Similar to *The Snake Pit*, *In Two Minds* elicited concern that viewers would not realise that the production was a dramatisation, because of its use of documentary techniques.<sup>60</sup> Writer Anthony Burgess wrote in BBC magazine *The Listener* in 1967 that *In Two Minds* was a 'dangerous hybrid' and 'not a play at all'.<sup>61</sup> *Daily Express* journalist James Thomas went further stating 'too often the drama spots are being used by writers and producers to air opinions so way out that they should not be shown to a massive lay audience without balance.'<sup>62</sup>

*Family Life*, a film remake of *In Two Minds*, was released in cinemas in 1971.<sup>63</sup> The story was much the same as *In Two Minds*, although with some key differences. The relationships within Janice Baidon's (Kate Winter in the original) family were explored, with an emphasis on her strained relationship with her parents. Similarly to *In Two Minds*, Janice lives with her parents when she is not in hospital, but there is little evidence of Janice's parents providing substantial care for her, particularly because her parents are represented as being to blame for her condition. Janice's sister reflects on this relationship, saying 'you've done this to her . . . this won't happen to my children'. In contrast to the final scene of *In Two Minds*, at the end of *Family Life* the consultant offers a diagnosis and prognosis for

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<sup>59</sup> R.D. Laing, 'What is Schizophrenia?', *New Left Review*, 1:28 (November-December 1964). First read as a paper at the First International Congress of Social Psychiatry.

<sup>60</sup> Hill, *Loach*, p. 74.

<sup>61</sup> Anthony Burgess, 'Television', *The Listener*, 77:1980 (9 March 1967), p. 335 cited in Julian Petley, 'Factual Fictions and Fictional Fallacies: Ken Loach's Documentary Dramas', in George McKnight (ed.), *Agent of Challenge and Defiance: The Films of Ken Loach* (Trowbridge, 1997), p. 28.

<sup>62</sup> James Thomas, 'Getting a Bit Blurred on TV . . . "Drama" and "Real Life"', *Daily Express*, 8 March 1967, p. 8, cited in Petley, 'Factual Fictions', p. 29.

<sup>63</sup> *Family Life* was also written by David Mercer, produced by Tony Garnett, and directed by Ken Loach.



Janice which, although taking a traditional, medical-model view of schizophrenia, is accepted by the trainee doctors without challenge. However, a critique of traditional psychiatry is included much more explicitly within the film itself. Whilst *In Two Minds* only depicted the views of a 'Laingian' psychiatrist via voice over, *Family Life* featured Dr Donaldson, a 'Laingian' psychiatrist, who treats Janice in the first half of the film. As part of this treatment, which her parents openly criticise, the psychiatrist interviews Janice's family and Janice enters a therapeutic–community-style ward. A therapeutic community is usually residential and involves those with severe mentally illness, including schizophrenia, living in a group environment with others, including therapists. Treatment methods include psychotherapy.<sup>64</sup> In contrast, when Janice enters a more traditional psychiatric ward run by Mr Carswell latter in the film, she receives involuntary ECT, one of the physical treatments opposed by Laing because of its barbaric nature. Under the care of Donaldson Janice's condition improves, but once in a more traditional setting her condition rapidly deteriorates and she becomes mute.

Loach wanted *Family Life* to seem as authentic and real as possible.<sup>65</sup> Dr Donaldson was played by a real doctor, Michael Riddall, and many of the patients in the group therapy sessions were schizophrenics living in a therapeutic community, the Philadelphia Association, established by Laing in 1965.<sup>66</sup> Riddall was encouraged to bring out the personalities of the actors playing the fictional family and Loach later commented that 'what emerged was almost a documentary about the people

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<sup>64</sup> Hill, *Loach*, pp. 123-24.

<sup>65</sup> For a discussion of whether audiences can distinguish between fact and fiction, see Greg Philo, 'Conclusions on Media Audiences and Message Reception', in Greg Philo (ed.), *Message Received: Glasgow Media Group Research, 1993-1998*, (Harlow, 1998), pp. 288-89.

<sup>66</sup> Hill, *Loach*, p. 124.

in the film'.<sup>67</sup> Janice's mother Vera was played by Grace Cave, who was cast at the Walthamstow Conservative Association's ladies committee meeting. Unaware that she had been cast in the role of a schizophrenogenic mother Loach later stated: 'in [Cave's] mind the mother was being as good a parent as she could be under the circumstances'.<sup>68</sup> Chosen for her traditional family views, Cave tells the psychiatrist in *Family Life* that: 'the permissiveness and the drug-taking . . . There must be more control over our younger generation.'<sup>69</sup> Like *In Two Minds*, *Family Life* evoked responses in the broader media. On 2 February 1972 a letter in the *Guardian* from social worker J.M. Scruby raised concern at the accuracy of the relationships portrayed in *Family Life*, as whilst 'the parents were all "bad"', in reality 'family dynamics in cases such as these are often much more subtle'.<sup>70</sup>

Shortly after *Family Life*'s release the parent group the National Schizophrenia Fellowship (NSF, 1972) was set up. Although not a direct response to the film's release, from the outset the NSF was highly critical of anti-psychiatry, which had been positively portrayed in *Family Life*.<sup>71</sup> The NSF's critique of anti-psychiatry created tension between the NSF and the service-user organisation, MIND, a mental health charity sympathetic to the anti-family and anti-institutional sentiment of *Family Life*. In particular, MIND supported service-user rights and hospital closures.<sup>72</sup> In 1980 NSF Chairman, John Pringle, reflected back on 'the damage done by sensational films and paperbacks by the "blame the family"

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<sup>67</sup> Graham Fuller (ed.), *Loach on Loach* (London, 1998), p. 44.

<sup>68</sup> *Ibid.*, p. 45.

<sup>69</sup> Hill, *Loach*, p. 125.

<sup>70</sup> Helen Young, 'Letters to the Editor: Schizophrenia, Laing, and Family Life', *Guardian*, 2 February 1982, p. 14.

<sup>71</sup> Sociologist Nick Crossley has referred to carer groups like the NSF as being part of an 'anti-anti-psychiatry' movement: Nick Crossley, *Contesting Psychiatry: Social Movements in Mental Health* (London and New York, 2006), p. 5.

<sup>72</sup> The discord between the NSF and MIND is examined in more depth in Chapter Five of this thesis.

schools of fringe psychologists' in the early 1970s, when *Family Life* was released.<sup>73</sup>

However, the NSF were reluctant to completely rule out non-traditional approaches to the treatment of those with schizophrenia. In 1970 Pringle explained that 'in the flux of often conflicting opinions about the causation and management of schizophrenia it would seem desirable that the society should avoid commitment, in the present state of knowledge to any one theory or school'.<sup>74</sup>

In 1981, social activist and NSF member, Peter Sedgwick went further, referring to 'the mass cult of "anti-psychiatry" when he explained that the public had fallen victim to the 'indoctrination of Laingian ideas'.<sup>75</sup> However, the extent to which the ideas of anti psychiatry were internalised by the population is arguable, but *In Two Minds* and *Family Life* certainly helped to disseminate these views. Although Laing began to reconsider his views on the relationship between schizophrenia and the family by 1972, the NSF were concerned that Laing's ideas would endure in the public imagination.<sup>76</sup> In response, the NSF concentrated on educating its members, professionals and the wider public, partly by obtaining their own media coverage, with their first television mention in 1976 on the Horizon programme *Pathway From Madness*.<sup>77</sup> The NSF reacted against anti-psychiatry and Loach's documentary-dramas by seeking to educate, or to re-educate, professionals and the public about the realities of schizophrenia and the experience of caring for

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<sup>73</sup> John Pringle, 'Breaking an Old Taboo', *The Times*, 26 June 1980, p. 18.

<sup>74</sup> WL, PP/DSI/B/2, *The Problem*, p. 3.

<sup>75</sup> John Wing and Clare Greer, 'Schizophrenia at Home', in Henry R. Rollin (ed.), *Coping with Schizophrenia* (London, 1980), p. 22. See: Peter Sedgwick, 'Foucault: The Anti-History of Psychiatry', *Psychological Medicine*, 11 (May 1981), p. 244; Peter Sedgwick, *Psycho Politics. Laing, Foucault, Goffman, Szasz, and the Future of Mass Psychiatry* (London, 1982), p. 4.

<sup>76</sup> WL, P/DSI/F/2, *The Early Years, A History of the National Schizophrenia Fellowship (now Rethink)*, (2004), p. 20; Charles Rycroft, 'Laing, Ronald David (1927-1989), Psychiatrist and Psychoanalyst' *Oxford Dictionary of National Biography* (Oxford, May 2009).

<sup>77</sup> WL, PP/DSI/F/1, *NSF: The first twenty-one years, 1972-1993* (September 1973), p. 4.

a relative with the condition. Thus, organisations like the NSF contributed to a much broader move at the time to acknowledge family carers. In particular, the NSF raised the profile of the experiences of family carers and their need for support.

Whether or not Loach's *In Two Minds* and *Family Life* persuaded the public that families were the cause of schizophrenia, as the NSF feared, the films had another impact in that shortly afterwards *Britain's* first reality television show, *The Family* (1974), was broadcast on BBC. *In Two Minds* and *Family Life* offered a window into the daily life of and relationships in an, albeit fictional, family. A fly-on-the-wall-documentary, *The Family* showed the day-to-day lives of members of the Wilkins who were often shown arguing with one another. With between seven and ten million viewers a night, this documentary, which could be viewed as a challenge to the family as 'the citadel of privacy', seemed to provide an insight in to the 'ordinary' family, although as historian Deborah Cohen has argued, the Wilkins family were not a typical family, not least because they allowed television cameras into their private home.<sup>78</sup>

*The Family* showed the viewing public that families without a mentally ill relative could have problems and arguments. Once anti-psychiatry had become less popular from the mid-1970s onwards, the notion that any family could be dysfunctional became more popular. Indeed, in a newspaper review of a repeat of *In Two Minds* in 1988 a journalist suggested that Laing's views on the relationship between mental illness and the family held less sway in the popular imagination by the late-1980s:

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<sup>78</sup> Cohen, *Family Secrets*, pp. 238-40.

R. D. Laing-inspired ideas no longer seem entirely satisfactory. In the Sixties it was fashionable to believe the family literally drove you mad, and certainly the Winter parents are the kind of ignorant, smug and small-minded people who would certainly induce problems in their children – but as an explanation of this most mysterious of illnesses it now seems a little thin, as probably half the population resemble them.<sup>79</sup>

In conclusion, anti-psychiatry and the media's interest in challenges to the family and mental institutions that its proponents presented, encouraged others with an interest in schizophrenia, whether from within the medical profession or non-governmental organisations, to join the debate and spread awareness of the role and experiences of the families of those with schizophrenia. In some respects the popularisation of Laingian ideas on the pathogenic relationship between the family and schizophrenia via Loach's films obscured the role of the family in the care of mental illness during the 1960s and 1970s. Rather than examining the role and experiences of family members, *In Two Minds* and *Family Life* mounted an attack on the relatives of schizophrenia sufferers, who were portrayed as being both the cause of the condition and a barrier to successful treatment. Although Laing later reappraised his critique of the family, these ideas were not widely discussed. However, the popularisation of ideas associated with anti-psychiatry also contributed to the growing awareness of the role of family carers of mental illness during the 1960s and 1970s. Laing, along with others who came to be associated with anti-psychiatry, triggered debate in print media, among professionals, and influenced the inception of parent-run organisations like the NSF who campaigned

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<sup>79</sup> Jeannette Kupferann, 'In Two Minds', *Daily Mail*, 21 July 1988, p. 26.

to re-educate the public about the realities of caring for a relative with schizophrenia.

Film proved an effective mode of representation for anti-psychiatry, because the theories of Cooper and Laing were heavily based on dynamic family relationships and dialogue between relatives. However, more important was that mental illness was portrayed as a family problem rather than a problem confined to, and indeed within, the individual. As with the documentaries produced by DKP, the environment of the family home had a key place in Loach's documentary-dramas. Whilst Loach's films were more critical of the family's role in treatment, both showed the British population an insight into the family life of individuals with a mental handicap or mental illness.

### **Channel 4 and Carer Voice, c. 1982-1999**

When Channel 4 first went on air on 2 November 1982 the major film shown on its first day of broadcasting was *Walter*, a film adaptation of David Cook's 1980 novel of the same name.<sup>80</sup> Telling the story of a mentally handicapped man forced into residential institutional care after the death of his parents, *Walter* contrasts the care provided by parents with that of the state. In the novel, although Walter's parents were portrayed as struggling to come to terms with Walter's handicap, with his mother contemplating murdering him at one stage, familial care was portrayed as preferable to the alternative provided by the state. Indeed, in the book, Walter's

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<sup>80</sup> David Cook, *Walter* (Harmondsworth, 1980); *Walter*, Dir. Stephen Frears (Network, 2011).

mother told Walter's head teacher: 'I could have achieved far more by keeping him at home and teaching him myself, than what your so-called "special school" has.'<sup>81</sup>

That Channel 4 chose to air *Walter* as part of its inaugural broadcast suggests that it thought the film would draw a large audience and provoke debate, thus drawing greater attention to the fledgling channel. Indeed, the film adaptation of *Walter*, contrary to the book, began with the shocking scene when Walter's mother considers murdering him. The relationship between Walter and his mother is portrayed as complex in the film. She is shown caring for him by waking him, bathing him, and explaining tasks to Walter so he could complete them himself. Walter's mother was shown becoming frustrated with Walter on a number of occasions, when he was unable to write his name as a child and when the pair struggle to communicate effectively with each other. In contrast, Walter's father took a largely passive role in Walter's care much to the frustration of his wife. Whilst the film omits the scene with Walter's mother and the head teacher, the home environment was clearly shown as preferable to the institutional setting where Walter is later sent. Although Walter had previously had a job, he received no rehabilitative care in the institution and was shown caring for patients less-able than himself. Walter's mother asked early on in the film 'what will happen when I'm gone?' The film closes with one of the institution's staff explaining to Walter: 'by rights you shouldn't be here and if your parents were still alive you wouldn't be.'

In April 1989 media studies academic J. Mallory Wober published a pamphlet entitled *Healthy Minds on Healthy Airwaves* in which he stated that between October and November 1986, of the fourteen programmes he was aware

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<sup>81</sup> Ibid., pp. 56-57.

of broadcast on the topic of mental health, twelve were shown on Channel 4.<sup>82</sup> As part of Channel 4's tendency to air programmes on the theme of mental health, these programmes also raised the profile of, and contributed to debates about, family carers. However, many of these documentaries, including *Back to the Community* (1986), focused on the experiences of patients, or 'clients', moving out of long stay institutions and seeking an independent life in the community with little focus on the role of the family. This is unsurprising given that some service-users became their own main carers in the community.<sup>83</sup>

By the mid-1990s, the role of the carer was becoming widely acknowledged and discussed, but also challenged, for instance with concerns over the emotional well-being of carers. On 23 July 1996 *Edge of Madness*, a documentary directed by Diane Tammes and Maggie Ellis, was aired on Channel 4, which was complemented by a pamphlet entitled 'Edge of Madness: Living with Schizophrenia'.<sup>84</sup> Part of the *True Stories* series, the documentary followed the daily lives of four people with schizophrenia, exploring treatment options including the side-effects of drug therapy Clozapine, and family therapy under the direction of social psychiatrist Julian Leff, of the Medical Research Council's Social Psychiatry Unit. *Edge of Madness* considered the view-points of service-users and medical professionals, but also relatives. The well-being of relatives was explored in terms of burden and the potential for violence. During a therapy session with the Bellamy family, led by therapist Jerome Carson, the following exchange took place:

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<sup>82</sup> J.M. Wober, *Healthy Minds on Healthy Airwaves: Effects of Channel 4's 1986 Mental Health Programme Campaign* (London, 1989).

<sup>83</sup> Peter Barham, 'From the Asylum to the Community: The Mental Patient in Postwar Britain', in Marijke Gijswijt-Hofstra and Roy Porter (eds), *Cultures of Psychiatry and Mental Health Care in Postwar Britain and The Netherlands* (Amsterdam, 1998), p. 223.

<sup>84</sup> *Edge of Madness*, Dir. Dianne Tammes and Maggie Ellis (Channel 4, 1996).



James' Sister: It's not a question of us saying sod off you've got your medication now, it's a case of saying well I'm not going to sacrifice everything for you but I am here because I care for you, but not because I am a carer and that's the difference.

James' Father: And this is why I am not his carer in that technical sense that carer is now understood. We care and I'm his father, and I'm his mate and he's always got a place with me when he wants to, but it's all to do, I think, with James also taking on his illness.

James' relatives were aware of their conceptualisation as carers but were willing to actively challenge and resist this designation. Another relative featured in the documentary, Carole Gates, whose son Barrie had schizophrenia, stated:

We just don't matter, but we *do* matter. And this government *need* us. If they want this community care, they need people like me, people who are prepared to take on a son full-time. . . you have to *live* with the illness twenty-four hours a day, year in and year out. Then you can say that you understand it.

Carole demonstrated an awareness of the role she was expected, and required, to fulfil in the care of her son Barrie. Whilst willing to carry out this role, Carole expected support from the state. Like James' father, Carole provided care and support for her son but was reticent to assume, uncritically, the role of carer.

Many of the newspaper articles that discussed the documentary sought to educate readers about the facts of schizophrenia. A 23 July 1996 *Daily Mail* review stated: 'schizophrenia . . . directly affects about one per cent of the British population - and indirectly affects many more, notably the victim's families', who have been through "terrible ordeals".<sup>85</sup> On the same day the *Guardian* published an article written by Assistant Editor of the *British Medical Journal*, Trish Groves, which offered detailed factual information about schizophrenia. The article, in support of the social psychiatric approach of Julian Leff, explained how, with the help of a psychiatrist, James Bellamy's 'family helped him overcome the disease'.<sup>86</sup>

A *Daily Express* review noted 'the clear devotion of a family which, . . . knew they had to rally to their sick member'.<sup>87</sup> However, in an article inspired by the work of R.D. Laing from the 1960s and 1970s, film critic Jonathan Romney questioned the ethics of the film making process which itself 'seemed to reproduce the dissociations and fragmentations you associate with the illness'. Romney also picked up on the relationship between Miranda, another patient featured in the documentary, and her mother: 'Miranda, articulate and pained, kept being sardonically cut off by her mother'.<sup>88</sup> The different reactions from the press to *Edge of Madness*, especially regarding the relationship between schizophrenia and the family, suggests that this relationship continued to be complex and contentious in the 1990s.

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<sup>85</sup> 'Best Documentary', *Daily Mail*, 23 July 1996, p. 42.

<sup>86</sup> Trish Groves, 'Mind Field', *Guardian*, 23 July 1996, p. A14.

<sup>87</sup> 'Television Last Night with Roy Hattersley', *Daily Express*, 24 July 1996, p. 41.

<sup>88</sup> Jonathan Romney, 'Truly, Madly: Television', *Guardian*, 24 July 1996, p. A9.

On 7 March 1999 Channel 4 aired *Access All Areas: The Down's Syndrome*, a documentary directed by Cilla Ware and produced by Hart Ryan Productions.<sup>89</sup> *The Down's Syndrome* was critical of the medical profession and campaigned for the rights of people with down's syndrome to access adequate medical treatment. The film was based on the results of a survey conducted by the Down's Syndrome Association (DSA). In 1996 Carol Boys, whose son Alex was born with Down's Syndrome in 1983, became the Chief Executive of the DSA. In the documentary she talked of the 'blatant prejudice' towards people with Down's Syndrome in their encounters with the medical profession where they are sometimes treated as 'second-class citizens, not worthy of treatment'. The main dialogue in the documentary, however, came from the parents of those affected. For instance, Karen Dance, mother of Natalie, explained that she was told her daughter's hole in the heart was inoperable. The voice-over stated that Karen was unwilling to 'simply wait for her to die' and the operation was performed after the family sought a second opinion from Great Ormond Street Hospital. Karen described an encounter she later had with Natalie's initial paediatrician. Karen informed the doctor of the successful operation, to which he replied 'yes, but who's going to look after her when she's older?' and cited cost as a factor in his initial decision. Karen, like the other parents featured in the programme, felt her child should be treated like any other sick child: 'I wouldn't swap Natalie for ten normal children . . . she's just leading a normal life.'

Documentary film-makers during the 1990s were not solely responsible for family carers finding a voice and joining public debates about their role in mental

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<sup>89</sup> *Access All Areas: The Down's Syndrome*, Dir. Cilla Ware (Hart Ryan Productions, 1999).

health care. Indeed, as discussed in Chapters Four and Five of this thesis, carer groups including Mencap and the NSF aimed to educate the public about the facts about mental illness and disability, including the everyday experiences of carers. This was, in part, a response to public misconceptions, including that those with schizophrenia were violent and dangerous. The NSF, for example, encouraged its members to become 'media volunteers', speaking to the press and acting as consultants on television and radio programmes. The NSF also held local parent support groups where relatives could share their experiences with other carers. By the mid-1990s, then, many caring relatives, particularly members of carer groups, were used to describing, and in some cases interrogating, their role as carers. By sharing experiences in support groups, watching other carers speak about their lives on documentaries, and describing their needs and concerns to medical practitioners, carers had become more comfortable and adept at applying a narrative to their experiences. As is evident from the view expressed by the relatives in *Edge of Madness*, at least some carers were aware of the socio-political debates surrounding the place of the carer within social care provision and were able to engage with these ideas. It is likely that some of these parents, at least, were used to sharing their experiences by the 1990s, whether via a mutual support group or by partaking in family therapy sessions. Television documentaries provided another vehicle for carers to share their experiences and introduced the day-to-day lives of carers and how they felt about their identification as 'carers' to a broader public audience.

## Conclusions

In conclusion, this chapter has used film and television documentaries and documentary-dramas to examine media portrayals of the place of the family carer in post-war mental health care. The role of families in the care of people with mental handicaps and physical handicaps was represented in documentary films almost a decade earlier than relatives caring for people with mental illness. These early films from the 1960s were commissioned by parent and carer groups, and reflected an increasing awareness of the familial care of handicap within the home during the 1960s and the immediate post-war decades. Parents were encouraged to allow medical and educational professionals to train them how to support the development of their child within the home. The films produced by Derrick Knight & Partners (DKP) were an ideal medium to educate other parents and the public about this parental role. Because parents could be seen and heard interacting with medical professions, caring for their children, and by filming within the family home, this care environment became more familiar to those who watched the films.

Whilst the DKP films were shown to groups, and occasionally on television, Loach's films, *In Two Minds* and *Family Life*, had a wider release. Unlike the DKP films, Loach's documentary-dramas focused on the pathological, rather than therapeutic, role of the family. The parents were shown expressing concern for their daughter, but not adopting a caring role per se. In response, organisations including the NSF worked to redress this view in the public-eye and instead tried to

demonstrate the burden placed on parents caring for those with schizophrenia. By the 1980s, Channel 4 took a lead in airing programmes on the theme of mental illness. In these films and documentaries relatives were given a more three-dimensional portrayal. The family environment could be therapeutic or pathological and relatives could want to actively negotiate or challenge their designation as carers.

As demonstrated in Chapter Two of this thesis, the family and the family home became increasingly opened up and demystified by sociological researchers during the second-half of the twentieth century. These social researchers also examined families with a mentally ill or mentally handicapped relative, focusing on the home environment, social relationships, and the well-being of family members. In the post-war years, television and film producers became interested in the topic of the family. Cohen has observed that the family went from being perceived as 'the building block of society' after the Second World War to 'powerful and destructive' by the 1970s.<sup>90</sup> However, as demonstrated in this chapter, these portrayals gave varying views of the nature of family, as well as the family's capacity to care. The media of film and television were particularly well-placed to explore the relationships between mental health care and the family because they brought family dynamics, dialogue, and relationships to life for viewers. The relationship between families and their mentally ill or mentally handicapped relatives are shown as complex, with some families providing care, others concern, and some wanting to unburden themselves. The importance of these television programmes and films also lies in their role of eliciting debate within newspapers and beyond, giving the

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<sup>90</sup> Cohen, *Family Secrets*, p. 214.

public a better grasp of a variety of perceptions of the day-to-day experiences of family carers. As family carers themselves became more aware of the paradox of family as both pathology and therapy, in part because of television and film representations, they became better equipped to negotiate their identities. Indeed, by the 1990s relatives were given a voice in these documentaries, at times rejecting their designation as 'carers'. The medium of film played a role in bringing the social dynamics of families to life, including families with a relative with a mental illness or learning disability. Documentaries and documentary-dramas encouraged viewers to see the complexity of life and relationships within these families, and therefore played an important role in the emergence of the carer as a public figure.

# 4.

## **Mencap and the Family Carer, c. 1946-1999**

This chapter examines the case study of Mencap from its inception in 1946 until the House of Lords debate on the Mencap chairman Lord Brian Rix's Private Members Bill, the Disabled Persons and Carers (Short Term Breaks) Bill, in 1996. Mencap has been selected as a case study because it was the first national parents' organisation for mental handicap in Britain. Founded in 1946 by Judy Fryd, just over twenty years before the National Schizophrenia Society (NSF), the National Association of Parents of Backwards Children (NAPBC), as Mencap was initially called, was a pioneering parent group. By 1968 Mencap had 30,000 members comprising families, medical professionals, social workers, and other interested parties. The organisation changed its name to The National Society for Mentally Handicapped Children (NSMHC) in 1955 and The Royal Society for Mentally Handicapped Children and Adults in 1981. Known by the shortened version of its name, Mencap, since 1969 the organisation was established in the 1940s at a time when professionals were encouraging the familial care of children with life-long, chronic mental and physical handicaps. The National Association was set up in direct response to the 1944 Education Act, which had deemed many children with mental



handicaps 'ineducable'. The NAPBC resisted this legislation, campaigning for mentally handicapped children to receive an education. The Association was pivotal in legislative change, including the passing of the 1970 Education Act. The activities of the group also raised awareness of the role of parents as both carers and spokespeople for their children.

This chapter examines Mencap with a specific focus on two of its main activities: its efforts to improve the services and opportunities available for mentally handicapped children; and its work to improve the quality of life of their families, including respite for parents. Firstly, I provide an account of the inception of the NAPBC in 1946 until the 'Brooklands experiment' of 1958, which compared the progress of mentally handicapped children living in a hospital with those in a small, family-style environment. I demonstrate that the NAPBC encouraged parents to care for, train, and educate their handicapped children in the home and began to establish services to advance this objective. Secondly, I examine the activities of the NSMHC in the 1960s and 1970s. The organisation continued to train parents and encourage them to act as medical and educational spokespeople for their handicapped children. I show that the NSMHC raised its profile during these years, successfully campaigning for mentally handicapped children to be deemed 'educable'. Thirdly, I focus on the period from the 1980s to the mid-1990s when Mencap campaigned for carers to receive needs-based assessments and benefit from respite in the form of short-breaks. I argue that from its inception Mencap perceived parents, and in particular mothers, as a key asset and positive influence in the lives and development of children with mental handicaps. Mencap sought to improve the lives of mentally handicapped children and their families by

campaigning to improve their life chances and opportunities, but also by providing a broad range of services. The activities of Mencap had an important role in the extension of education and employment opportunities for those with mental handicaps. Further, Mencap had a role in the emergence of the family carer and helped to reinforce this category by consistently underlining the important role parents played in the care and development of children and adults with learning disabilities. Mencap encouraged parents to become not only carers, but also spokespeople for their children.

### **Early Years: NAPBC, c. 1946-1955**

Judy Fryd's first daughter Felicity was born in 1938. Felicity, who had an intelligence quotient (IQ) of forty-three, showed signs of what was then called mental deficiency. Reluctant to send her daughter to a long-stay residential institution, Fryd taught Felicity her alphabet and how to count. Although initially being accepted into a local primary school and a special boarding school, Felicity was sent home from both due to being 'too disruptive' and 'not suitable', respectively.<sup>1</sup> By the mid-1940s the educational opportunities available to children like Felicity were further restricted following the passage of the 1944 Education Act. The Act ruled that local education authorities should organise for all children over the age of two 'suffering from a disability of mind of such a nature or to such an extent as to make him incapable of receiving education at school' to be examined by a medical officer.

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<sup>1</sup> Brian Rix, 'Fryd, Caroline Joyce (1909-2000)', *Oxford Dictionary of National Biography*, (Oxford, 2004).

The medical officer could then report that the child was 'incapable' of being educated at a school or special school, which could be on the grounds either of the child's own inability to learn or because it was 'inexpedient' for them to be educated in a group setting.<sup>2</sup> Whilst historians often state that this Act deemed these children to be 'ineducable' the document did not actually use this term. The 1944 Education Act was not substantially revised until 1981 when the new Education Act gave all children the right to a full-time education. The current secondary literature on special education post-1944 is sparse, and does not pay much attention to the influence of voluntary groups over education reforms. However, these organisations, and in particular the NAPBC, played an influential role.<sup>3</sup>

In response to the 1944 Act, Fryd continued to educate her daughter at home and campaigned for the education of not only her daughter, but other children with severe mental handicaps. In 1944 Fryd began to work with the National Association for Mental Health (NAMH, later MIND) to challenge the assumptions of the 1944 Education Act.<sup>4</sup> In her actions, Fryd was acting counter to the psychological basis for the 1944 Education Act which was inspired by the work of educational psychologist Cyril Burt who asserted that intellectual ability was 'inherited, or at least innate, not due to teaching or training'. In this respect, Burt thought that intelligence could 'be measured with accuracy and ease'.<sup>5</sup> The 1944

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<sup>2</sup> *Education Act*, 7 & 8 Geo. v1, ch. 31 (1944), pp. 45-47.

<sup>3</sup> For an overview of the history of special education post-1944 see: Adrian Wooldridge, *Measuring the Mind: Education and Psychology in England, c. 1860-1990* (Cambridge, 1990).

<sup>4</sup> Stanley Solomon Segal, *No Child is Ineducable: Special Education – Provision and Trends* (Oxford, 1967), pp. 5-6.

<sup>5</sup> Cyril Burt, *How the Mind Works* (London, 1934), pp. 28-29. See also: Mathew Thomson, 'The Psychological Body', in Roger Cooter and John Pickstone (eds), *Medicine in the Twentieth Century* (Abingdon, 2000), p. 296-97.

Education Act used this theory as the basis for barring mentally handicapped children from receiving a normal education. The 1944 Act was of particular concern to parents of children who were 'borderline' cases because their parents felt they were capable of receiving a normal education. The inception of the NAPBC, then, should be seen as a direct response to the 1944 Education Act.

In 1946 a letter appeared in *Nursery World* magazine written by a desperate mother asking whether others were struggling to care for their mentally handicapped children at home. A subsequent issue of *Nursery World* included a response from Fryd in which she enquired whether other parents were attempting to educate their mentally handicapped at home and whether they should create a group of parents to be better placed to lobby social services, health, education, and local authorities. Fryd later reflected: 'I wrote a letter . . . suggesting that parents of backward children should band together to press for the facilities we needed . . . for, being excluded from school, our children were deprived of many things – no ration of free milk, no family allowances'.<sup>6</sup> Within a month of the letter's publication, and subsequent articles in the *Sunday People*, Fryd was contacted by around 1000 parents and in 1950 the NAPBC was formally established. As the NAPBC developed, Fryd continued her role of correspondence with parents and families through being editor of the society's newsletter *Parents' Voice* which will be examined later on in this chapter.

An influential factor in the NAPBC's inception was Judy Fryd's background. As an economics and political science graduate from Oxford, Fryd not only had the personal experience of caring for a daughter with a learning disability, but also had

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<sup>6</sup> Brian Rix, *All About Us! The Story of People with a Learning Disability and Mencap* (London, 2006), p. 26.

the professional expertise, contacts, and indeed, cultural capital required to found a parents' group.<sup>7</sup> Via her contributions to *Nursery World* and the *Sunday People*, Fryd reached out to other parents who had similar experiences and concerns as herself with the aim of setting up a parents' group to provide mutual support and campaign for change. When Doris Drown, who went on to become an active member of the NAPBC, found out her son Derek was mentally defective and would not be able to attend a normal school she 'knew no-one and I mean no-one with a mentally handicapped child. I didn't know where to go, where to begin.' Drown was one of the parents who responded to Fryd's letter and she found the membership of the NAPBC to be supportive.<sup>8</sup> The parents who contacted Fryd wanted their children to receive an education. The formation of the NAPBC offered these parents the social capital they needed to begin to set up their own services and to apply pressure on the government to reform related legislation. From the outset, Fryd was keen for the NAPBC to interact with the state and gain membership from other key parties, including medical professionals, to enhance the group's influence.

Another significant factor that led to the inception of the NAPBC in the early post-war years was contemporary understandings of the role of parents in child development, including the development of mentally handicapped children. As historian Mathew Thomson has argued, a policy of community care existed for mental deficiency decades before the Mental Health Act, despite 1959 often being proposed as a key watershed moment in the history of deinstitutionalisation. The range and nature of provision differed from that of the post-war years and the

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<sup>7</sup> Pierre Bourdieu, 'The Forms of Capital' in Richardson (ed.), *Handbook of Theory and Research for the Sociology of Education* (Westport, 1986), pp. 234-44.

<sup>8</sup> *Parents Voice*, 22:2 (June 1972), pp. 4-5.

options available in the inter-war years - supervision, guardianship, and occupation centres - were intended to bring the institution out into the community.

Nevertheless, by 1939 over 46,000 mental defectives were being cared for in the community.<sup>9</sup> Whilst some families cared for mentally handicapped relatives throughout the twentieth century, 'the authorities were reluctant to allow the parents or families of defectives to serve as guardians in the community' during the inter-war years.<sup>10</sup> In the post-war years this began to change as families, and in particular mothers, were increasingly thought to have a positive influence on the development of all children, including those with mental handicaps. Historian Deborah Cohen has explained that from the 1940s onwards, families who strove to look after their child at home broke the privacy, shame, and secrecy that surrounded mental deficiency earlier in the twentieth century. Cohen states that the parents 'returned to the Victorian trope of the pitiable and eternal child.'<sup>11</sup> However, some, including members of the NAPBC, felt that their children could be educated and improved. Indeed, by the 1970s and 1980s some of these parents campaigned for their children to enter mainstream education as part of the normalisation agenda.<sup>12</sup>

Building upon experiments during the Second World War, governments, the medical profession, and educational psychologists including Cyril Burt, increasingly recognised the value of social scientific methodologies including the social survey

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<sup>9</sup> Mathew Thomson, *The Problem of Mental Deficiency: Eugenics, Democracy, and Social Policy in Britain c. 1870-1959* (Oxford, 1998), p. 149, pp. 178-79.

<sup>10</sup> *Ibid.*, p. 169.

<sup>11</sup> Deborah Cohen, *Family Secrets: The Things We Tried to Hide* (London, 2014), pp. 110-12.

<sup>12</sup> Anne Borsay and Pamela Dale, 'Introduction: Disabled Children – Contested Caring', in Anne Borsay and Pamela Dale (eds), *Disabled Children: Contested Caring, 1850-1979* (London, 2012), p. 12; David Wright, *Downs: The History of the Disability* (Oxford: Oxford University Press, 2011), pp. 146-47.

and intelligence testing to 'measur[e] the characteristics of people'.<sup>13</sup> These instruments of social inquiry were employed in a variety of ways, including to measure the parameters of normality which came to be applied to the study of the family, child development and disability.<sup>14</sup> These methods of assessing whether families and their children were normal or abnormal interacted with assertions from child psychologists, including John Bowlby and Donald Winnicott, that the family was the ideal place for children to be raised.<sup>15</sup> In social policy, in psychiatric literature, and within child guidance, parents were assumed to have a direct and significant role in their child's future. This led to a proliferation of child guidance literature aimed at parents and based on child developmental stages.<sup>16</sup> As historian Harry Hendrick has argued, children were particularly liable to be ascribed to the flexible normal/abnormal binary because 'as a group, children are seen as embodying "the future"', and were a means for protecting the economic, social and political future of the state. In this context, 'backwards' children became more visible and some of these children's parents, having internalised the concept of

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<sup>13</sup> David Armstrong, 'Medical Sociology', in W.F. Bynum and Roy Porter (eds), *Companion Encyclopaedia of the History of Medicine* (London, 1993), p. 1643. For a more detailed examination of post-war social science see Chapter Two of this thesis.

<sup>14</sup> Mathew Thomson, *Psychological Subjects: Identity, Culture, and Health in Twentieth-Century Britain*, pp. 110-14; Adrian Wooldridge, *Measuring the Mind: Education and Psychology in England, c. 1860-1990* (Cambridge, 1990).

<sup>15</sup> Angela Davis, *Modern Motherhood: Women and Family in England, c. 1945-2000* (Manchester, 2012), pp. 112-36; Harry Hendrick, *Child Welfare: England 1872-198* (London and New York, 1994), p. 15; Mathew Thomson, *Lost Freedom: The Landscape of the Child and the British Post-War Settlement* (Oxford, 2013), pp. 79-93.

<sup>16</sup> Anne Borsay, 'From Representation to Experience: Disability in the British Advice Literature for Parents, 1890-1980', in Anne Borsay and Pamela Dale (eds), *Disabled Children: Contested Caring, 1850-1979* (London, 2012), pp. 91-101; Harry Hendrick, *Children, Childhood, and English Society, 1880-1990* (Cambridge, 1997), pp. 28-32; Thomson, *Psychological Subjects*, pp. 114-17.

children as future investments, strove for their children to have a normal life, facilitated by access to education.<sup>17</sup>

A shortage of places in long-stay institutions and barred access to boarding schools for handicapped children, which had increasingly long waiting lists, placed further pressure on parents to care for their mentally handicapped children within the home.<sup>18</sup> However, contemporary notions of children as 'future investments', coupled with concerns over 'problem' families, and cycles of deprivation, meant that medical professionals and politicians were reluctant to trust all families and homes.<sup>19</sup> In this context, efforts were made by medical professionals and child development specialists to encourage parents, especially those from the working classes, to care for their handicapped children in the home, but only with training and guidance from experts.<sup>20</sup> Indeed, in 1946 psychiatrist, advisor to the Ministry of Health, and Secretary of the Eugenics Society, C.P. Blacker noted that 'a large part of child psychiatry consists of guiding and advising parents'.<sup>21</sup>

In the early post-war years, therefore, parents of mentally handicapped children tended to care for their children within the home, whether because of the influence of child guidance literature which instilled a sense of duty in parents, a lack of available places in institutions, or a combination of the two factors. In

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<sup>17</sup> Thomson, 'Psychological Body', p. 296. See also, Borsay and Dale, 'Introduction', p. 12; Wright, *Downs*, pp. 146-47.

<sup>18</sup> Rex Brinkworth and Joseph Collins, *Improving Babies with Down's Syndrome* (2<sup>nd</sup> edn, Newcastle, 1973), p. 43.

<sup>19</sup> Hendrick, *England*, pp.14-15, p. 291; Harry Hendrick, *Child Welfare: Historical Dimensions, Contemporary Debate* (Bristol, 2003), pp. 13-14. For more on cycles of deprivation and problem families see: John Welshman, *From Transmitted Deprivation to Social Exclusion: Policy, Poverty, and Parenting* (Bristol, 2007); John Welshman, *Underclass: A History of the Excluded, 1880-2000* (London, 2006), pp. 79-137.

<sup>20</sup> Borsay and Dale, 'Introduction', p. 9; Matthew Smith, 'Hyperactivity and American History, 1957-Present: Challenges to and Opportunities for Understanding', in Anne Borsay and Pamela Dale (eds) *Disabled Children: Contested Caring, 1850-1979* (London, 2012), pp. 176-77.

<sup>21</sup> C.P. Blacker, *Neurosis and the Mental Health Services* (London, 1946), p. 21.



addition, many parents had looked after mentally handicapped children throughout the twentieth century, but this phenomenon became more visible from the 1940s onwards when the stigma related to mental deficiency was in decline, as part of a backlash to the eugenics movement following the Second World War.<sup>22</sup> The parents who joined the NAPBC wanted to be able to access information and support, but at the same time relevant professional experts wanted these parents to access training and guidance information to ensure that they were providing appropriate support for their handicapped children.

The first edition of Fryd's NAPBC journal, *The Parents' Voice*, stated the aims and objects of the Association:

#### OBJECTS

- (a) To promote the material, mental and spiritual welfare of backward children.
- (b) To foster mutual help and support among the parents and relatives of such children.
- (c) To promote closer co-operation and understanding between their parents and others responsible for their welfare.
- (d) To encourage research into the causes and treatment of mental handicap.

#### AIMS

- (a) That equality of educational opportunities should be made available for all children according to their needs and disabilities.
- (b) That a Government inquiry should be held in the Law and administration of Mental Deficiency.

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<sup>22</sup> Cohen, *Family Secrets*, pp. 110-12; Thomson, *Mental Deficiency*, p. 280.

(c) That improvements should be made in the care and training of the mentally retarded.<sup>23</sup>

In the same edition Fryd explained that:

The biggest achievement of our Association so far has been in bringing the parents and friends of these children together for their mutual advantage. In helping them to discard the sense of isolation and social frustration, the parents have been helped to enjoy their own children more, to face their personal problems with courage and hope, knowing that others are doing the same.<sup>24</sup>

The aims of the NAPBC contributed to a broader acknowledgement of the role of parents in the care of their mentally handicapped children during the 1950s. The NAPBC encouraged parents to support each other to more adeptly take on a caring role for their children, and in doing so urged parents to form, what historian Barbara E. Rosenwein has referred to as, an "'emotional community'".<sup>25</sup> The National Society also sought to represent the voice and views of parents to professionals and politicians. As the NSMHC reflected in 1969:

In the beginning we found, and catered for, an immediate need both for mutual comfort and helpful information, and the creation of a social life for these families,

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<sup>23</sup> *The Parents' Voice*, 1:1 (October 1950), p. 2.

<sup>24</sup> *Ibid.*, p. 3.

<sup>25</sup> Barbara H. Rosenwein, 'Worrying about Emotions in History', *American Historical Review*, 107:3 (2005), p. 284.

and for pressure on the public and authorities to provide these basic services which normal children have as a right.<sup>26</sup>

The NAPBC was able to raise its own profile by supporting the formation of local NAPBC groups across the nation and by becoming closely associated with other organisations including, the Friends of the Fountain Hospital, the NAMH, and the National Spastics Society.<sup>27</sup>

The NAPBC attempted to improve 'the care and training of the mentally retarded', by supporting the training of their parents, particularly their mothers. The NAPBC stressed the value of appropriate training and care in the early years of the child's life and that this would affect the child's future chances. Most probably, the NAPBC was influenced by child development theorists such as John Bowlby and notions of children as future investments. A feature in the January 1951 edition of *The Parents' Voice* stated:

The better the training of a backward child, the less work it makes in the home . . .  
Much of the feeling of frustration, of wasting valuable years in the child's life waiting for a vacancy in a Hospital or Institution, would be mitigated by some such scheme of training by the parents.<sup>28</sup>

The NAPBC actively addressed this issue by setting up services to assist with the training of parents and to support their caring role. In 1951 the NAPBC set up its

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<sup>26</sup> *Parents' Voice*, 19:3 (September 1969), p. 3.

<sup>27</sup> *Mental Health*, vii:1 (July 1947), pp. 13-14; *Mental Health*, ix:4, (Summer 1950), pp. 101-02; *The Parents' Voice*, 1:1 (October 1950), p. 2.

<sup>28</sup> *The Parents' Voice*, 2:1 (January 1951), pp. 6-7.

first parent-craft classes, initially organised locally by the Middlesex Regional Branch.<sup>29</sup> The NAPBC also acknowledged that training in isolation would not adequately support parents, who also needed access to services and respite. On 16 May 1952, the NAPBC opened an Occupation Centre, Orchard Dene, in association with the NAMH.<sup>30</sup> Orchard Dene was based in Liverpool where 14,000 mentally handicapped children were cared for at home. The centre was intended to help relieve 'the burdens borne by mothers who had handicapped children at home' by acting as a short-stay home 'where children could go during a domestic emergency.' Given the pressure on other institutions, it was hoped that 'Short-Stay Homes would, by giving parents a short respite, enable them to return refreshed to their task and to keep the children in the family circle.'<sup>31</sup> The establishment of services like Orchard Dene was in the spirit of the findings of the Feversham Report (1939) which had supported the voluntary provision of services for the mentally defective and mentally disordered in the community.<sup>32</sup> Additionally, the fact that this service was envisaged and spear-headed by parents demonstrates that families caring for mentally handicapped children wanted to provide care for their children at home but acknowledged the need for breaks and respite; in other words, in contrast to the inter-war era of the Feversham Report, the move to involvement of the voluntary sector was no longer simply a top-down process led by experts, mental hygienists, and philanthropists. MENCAP would continue to campaign for better access to services for family carers to have breaks from caring into the twentieth-first century.

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<sup>29</sup> *The Parents' Voice*, 2:3 (July 1951), p. 5.

<sup>30</sup> *Mental Health*, xi:3 (Summer 1952), p. 134.

<sup>31</sup> *The Parents' Voice* (July 1952), pp. 7-10.

<sup>32</sup> *The Voluntary Health Services: The Report of the Feversham Committee* (London, 1939).

On 12 November 1953 the work of the NAPBC was praised in Parliament for the first time, marking the first of many mentions of the Association in Hansard. Conservative MP William Shepherd explained that the '4,000 children awaiting entrance to an institution' was causing the families involved 'incredible hardship and distress.' Shepherd asserted that the NAPBC was 'helping the parents who are in this predicament to help themselves.' Fellow Conservative MP, Margaret Hornsby-Smith supported this sentiment by 'pay[ing] tribute to the institution at Orchard Dene, Liverpool. . . It is doing excellent work'.<sup>33</sup>

The NAPBC was afforded a more direct influence over Parliament when it was called to give evidence to the Royal Commission on the Law Relating to Mental Illness and Mental Deficiency, 1954-57. The NAPBC explained:

the main problem to be dealt with is the fact that large numbers of mentally handicapped and mentally sick children are left at home in the sole care of their parents for many years . . . The situation plays havoc with the family life, causes the children concerned to deteriorate and finally become a life-long burden on the State, and creates social problems which are not confined to the families concerned.<sup>34</sup>

The NAPBC campaigned for family allowances, better service provision, better training for mothers and Health Visitors, and closer liaison between the Health and Education Ministries. Indeed, the NAPBC had long been concerned about the negative impact of the designation of mentally handicapped children exclusively to

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<sup>33</sup> *Hansard's Parliamentary Debates*, 12 November 1953, vol. 520, cols. 1248-82.

<sup>34</sup> *The Parents' Voice*, 5:4 (October 1954), p. 3.

the Ministry of Health once deemed 'ineducable'. During questioning by the Royal Commission's committee the NAPBC stated that 'parents, would prefer, given adequate social services and help, to keep their children at home.'<sup>35</sup>

In January 1955 the NAPBC changed its name to the National Society for Mentally Handicapped Children (NSMHC), a move which followed a membership referendum. Mary Fryd, the figure-head of the no campaign, argued that since the inception of the NAPBC 'parents are now prepared to come into the open, as the parents of backwards children' and professionals showed 'a greater preparedness to make provision for the children.' The ultimately successful yes campaign, headed by Dudley Drown, argued that the change of name would attract new membership who were reluctant to join a parents' organisation. Up until this point the majority of the NAPBC's membership had consisted of parents from low-income families. Drown emphasised this point in his referendum manifesto and argued that he thought a change of emphasis in the Association's name would attract more families from higher-income families who would bring with them more money and influence.<sup>36</sup> On 14 March 1958 the NSMHC issued a revised memorandum and articles of associations which underlined the Society's desire to extend its influence by co-operating with all relevant international, national, and local groups and to assist government departments and authorities when advisable.<sup>37</sup>

The NSMHC continued to support research into the care of mental handicap, and Cyril Burt became the Chairman of group's Research Sub-Committee

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<sup>35</sup> *The Parents' Voice*, 5:4 (October 1954), pp. 3-6.

<sup>36</sup> *The Parents' Voice*, 5:3 (July 1955).

<sup>37</sup> Mencap Head Office, London, National Society for Mentally Handicapped Children, National Executive Committee Minutes, 13 July 1957-17 November 1962, *Memorandum and Articles of Association* (14 March 1958).

in 1954.<sup>38</sup> From 1957 psychologist Jack Tizard conducted a three-year study for the NSMC which became dubbed the 'Brooklands experiment'. Jack Tizard worked at the Medical Research Council's Social Psychiatry Unit and was a psychologist with an interest in psychology, medicine, education, and the social sciences. Tizard went on to become president of the British Psychological Society from 1975 until 1976. The experiment involved thirty-two children from the Fountain hospital who were divided into pairs of similar sex, age, IQ, and defect between the ages of four and ten. Half of the children stayed at the Fountain hospital whilst the others were sent to an experimental centre in Reigate. The children at Reigate were looked after in a small, family-like setting and were taught via an activity-based approach, similar to the way normal children were taught in nursery schools.<sup>39</sup> Tizard found that:

After one year the children [at Reigate] had increased eight months in 'mental age' as measured on a verbal intelligence test, as against three months for the controls. In personal independence they had increased six months as against three months for the controls.<sup>40</sup>

The design and findings of the experiment provided powerful ammunition for the NSMHC's campaign for the education and training of handicapped children in a family-style environment, rather than a medicalised hospital-setting. Indeed, Tizard

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<sup>38</sup> *The Parents' Voice*, 5:3 (April 1954), p. 3.

<sup>39</sup> Jack Tizard, 'Residential Care of Mentally Handicapped Children', *British Medical Journal*, 1:5178 (April 1960), pp. 1041-46. See also, Segal, *No Child*, pp. 77-78; Jack Tizard, 'An Experiment in the Residential Care of Mentally Handicapped Children', *Community Care of the Mentally Handicapped* (London, 1960); Jack Tizard, 'The Residential Care of Mentally Handicapped Children', *The Times Educational Supplement*, July 1960.

<sup>40</sup> Tizard, 'Residential Care', pp. 1044-45.

recommended small hostel living environments for mentally handicapped young people and adults.<sup>41</sup>

In conclusion, the NAPBC was founded at a time when the value of parents', and in particular mothers', involvement in the early-years care of all children was becoming recognised. Some health and child development specialists stressed the important role mothers could play in the early-years training of children, including mentally handicapped children. Judy Fryd, realised that children deemed 'ineducable' under the 1944 Education Act were indeed capable of learning and as such she grouped together with other parents to form the NAPBC to campaign for access to education to become universal. Rather than challenging the role ascribed to mothers as carers of mentally handicapped children, the NAPBC encouraged mothers to adopt this role by providing parents with training literature and favouring a home-style environment for raising these children. As parents of young children at a time when there were long waiting lists for institutions, these mothers were fulfilling the duty to care for their children. However, the NAPBC acknowledged that these parents required further guidance and support. The organisation established services so that parents, and in particular mothers, could be afforded a break from care-giving. Further, the NAPBC provided parents with an opportunity to discuss their issues with others in a similar position and to be part of an organisation campaigning on behalf of those with mental handicap, and their families.

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<sup>41</sup> John Welshman, 'Inside the Walls of the Hostel, 1940-74', in Pamela Dale and Joseph Melling (eds), *Mental Illness and Learning Disability Since 1850: Finding a Place for Mental Disorder in the United Kingdom* (Abingdon, 2006), pp. 207-08.



## Parents as Experts: NSMHC, c. 1959-1979

It was not until the 1971 Education Act that all children were deemed educable. However, the 1959 Mental Health Act had replaced 'ineducable' with 'unsuitable for education at school'.<sup>42</sup> Historians Matthew Hilton, Nick Crowson, Jean-François Mouhot, and James McKay, have argued that the NSMHC, or Mencap, was instrumental to the changes in 1959 and 1971 because of the Brooklands experiment, as well as the lobbying efforts of, and services provided by, the group.<sup>43</sup> In 1959, mentally handicapped children were reconceptualised as being 'trainable' and the 1959 Mental Health Act marked an important step in terms of local authorities being able to provide training centres for handicapped children. Educationalist Stanley Segal thought that this Act was significant because it meant mentally handicapped children 'were no longer ignored or left as a full-time responsibility to their hard-pressed parents.'<sup>44</sup> Even when a medical setting was deemed most appropriate for those with mental handicap, the NSMHC supported a hostel system designed to resemble a home setting rather than a hospital environment. Responding to the 1959 Act in the House of Lords, NSMHC Chairman Lord Pakenham argued that for patients who were likely to remain in hospital for life 'we must try to get hospitals approximating to a home.'<sup>45</sup>

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<sup>42</sup> Mental Health Act: 7 & 8 Eliz. 2., Ch. 72 (London, 1959), p. 103.

<sup>43</sup> Matthew Hilton, Nick Crowson, Jean-François Mouhot, and James McKay, *A Historical Guide to NGOs in Britain: Charities, Civil Society, and the Voluntary Sector since 1945* (Basingstoke, 2012), pp. 162-63.

<sup>44</sup> Segal, *No Child*, p. 6.

<sup>45</sup> *Hansard's Parliamentary Debates*, 19 November 1959, vol. 219, cols 783-868.

Following the 1959 Act, and the success of the NSMHC's efforts, other, more specialised, parents' groups for mental handicap emerged.<sup>46</sup> The National Spastics Society was founded in 1952 and the Autistic Children's Aid Society of North London, which later became the Autistic Society, was incepted in 1962. Both of these groups were set up by parents, although the Autistic Society also had early involvement from social workers. Despite their more limited focus, the National Spastics Society had similar aims to the NAPBC, with the intention of setting up services and disseminating information about cerebral palsy, whilst the Autism Society aimed to provide nursery groups as a form of specialised day care 'to prevent children being placed residentially'.<sup>47</sup> At a similar time, parent groups for the parents of physically handicapped children were also set up, with The Society for the Aid of Thalidomide Children being founded in 1962.

In 1960 the results of a questionnaire sent to members of a branch of the NSMHC were published in which a summary of the parents' views included the statement that 'entrance to an ESN [Educational Special Needs] school was obtained by continuous pressure by parents on local education authority'.<sup>48</sup> This statement suggests that parents who spoke up on behalf of their children and put pressure on professionals were more likely to have their perceived needs met. Membership of the NSMHC helped parents to better understand the opportunities available to them and how to discuss these with professionals. In 1960 Janet E.L.

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<sup>46</sup> Nick Crossley, *Contesting Psychiatry: Social Movements in Mental Health* (London and New York, 2006), pp. 1-9, pp. 20-21.

<sup>47</sup> WL, Addis, Robina, National Association of Mental Health, PP/ADD/D.17, *The Handicapped Child and his Parents in the Community* (1964), p. 6; Memorandum and New Articles of Association of the Spastics Society (London, June 1953), pp. i-iii.

<sup>48</sup> Segal, *No Child*, pp. 75-76.

Barclay, the mother of a 'mongol' daughter who was 'permanently at home', described her positive experience of the NSMHC:

the mother of a mentally handicapped child . . . took me to the local branch meeting of the National Society for Mentally Handicapped Children and I am convinced that that introduction was my turning point . . . It is in the first few months that we need help from someone who has been in the same situation.<sup>49</sup>

From 1960 parents could also take advantage of Gateway Leisure Clubs run by the NSMHC to 'provide respite for parents'.<sup>50</sup>

In 1960 the NSMHC published a pamphlet on *Improving Babies with Down's Syndrome* written by educational psychologist Joseph Collins and child psychologist Rex Brinkworth. The pamphlet encouraged parents to seek help and assistance to support the care they provided for their mentally handicapped child at home. *Improving Babies* was intended 'for the guidance of parents' and 'emphasised that training should begin as early as possible in order to obtain the most favourable results'.<sup>51</sup> It stressed the important role played by the mother, in what was referred to as therapeutic mothering:

Mongol babies need a proper home and mother to look after them from the start. Not only is pre-school nursery education too late but it does not involve mothers in the treatment of babies. . . Only in a real loving home can [mongol children] get the experiences that will wake up their minds . . . We use art and play to 'train the

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<sup>49</sup> Ibid., pp. 76-77.

<sup>50</sup> *Mencap News*, 29 (November 1992), p. 13.

<sup>51</sup> Brinkworth and Collins, *Improving*, p. 2.

senses', help the muscles work together and to involve mother actively with the child.<sup>52</sup>

Whilst the pamphlet stated that 'Down's babies thrive best in their own homes', their mothers were encouraged to seek advice and support, and the authors thought 'educational authorities should appoint teachers to visit homes and guide mothers from the earliest months.'<sup>53</sup> In addition to contacting doctors and health visitors, parents reading the pamphlet were advised to join the NSMHC 'to meet and talk with other parents' and to take advantage of the society's services including pre-school nurseries, holiday homes with short-stay care, and toy libraries.<sup>54</sup> Rex and Brinkworth recommended that 'after home treatment children proving to be high grade should enter pre-school groups with ORDINARY [*sic*] children.'<sup>55</sup> The pamphlet advised that 'good perinatal care . . . and immediate love from the mother are vital' and as such the guide attempted to persuade mothers that they could make a difference in their child's development.<sup>56</sup> This was in line with a broader school of thought at the time, strongly associated with child psychologist John Bowlby, which argued that a mother's love, bonding, and attachment was beneficial to the successful development of her child.<sup>57</sup> Brinkworth and Collins were extending this theory to mentally handicapped children and their mothers.

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<sup>52</sup> Ibid., pp. 43-44, p. 51.

<sup>53</sup> Ibid., p. 43.

<sup>54</sup> Ibid., p. 6.

<sup>55</sup> Ibid., p. 54.

<sup>56</sup> Ibid., p. 8.

<sup>57</sup> John Bowlby, *Child Care and the Growth of Love* (2nd edn, Harmondsworth, 1965).

During the 1960s the work of the NSMHC was increasingly recognised by, and mentioned, within parliamentary debates.<sup>58</sup> Part of the reason for this was the increasing membership of the Society, which by 1968 had 30,000 members, twelve regional offices, and many more local groups. As the Chairman of the Bedford branch noted in 1957, 'a much larger membership is necessary both of parents and others, if a true understanding is to be given to the public of the problem of mental handicap'.<sup>59</sup>

Another reason for the Society's higher profile was that members of the House of Lords, Earl of Longford and Lord Grenfell, were Chairman and Treasurer of the NSMHC, respectively. Longford and Grenfell campaigned on behalf of the views of the NSMHC membership, for example, during the Hospital Plan debate of 14 February 1962.<sup>60</sup> In 1966, NSMHC Chairman, Lord Segal praised the NSMHC's work. Segal argued that although the NSMHC had established services similar to those offered by the state and the NAMH:

there is an especial merit that this similar work should be carried out on the initiative of the parents of mentally handicapped children themselves. Through their own deep personal involvement, they bring to bear a special sympathy and understanding which is a vital element in the progress of this work. It is work which cannot be done in the same way by other agencies. . . These parents are anxious to

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<sup>58</sup> Hilton, Crowson, Mouhot, and McKay, *Historical Guide*, pp. 162-65.

<sup>59</sup> Bedford and Luton Archives and Records Service (BLARS), Records of Bedford Mencap, X682/1/2, Bundle of Annual General Meeting Minutes, 1955-1962, *AGM Minutes* (31 December 1957), p. 1.

<sup>60</sup> *Hansard's Parliamentary Debates*, 14 February 1962, vol. 237, cols 472-581.

de-institutionalise these hospitals and to humanise them in every conceivable direction.<sup>61</sup>

Parents who were members of the NSMHC spoke on behalf of their children during encounters with medical and educational professionals to try and improve their child's quality of life. It is likely that these parents had internalised the sentiment of child guidance literature from the 1940s and 1950s that parents, and in particular mothers, greatly influenced the development and future chances of their children. On 18 February 1966 Labour Co-Operative MP, Alf Morris, explained that 'parents of educationally subnormal children', including members of the NSMHC,

are acutely conscious of their responsibilities. Where there is an emotional blockage to learning, resulting, for instance, from divorce and the breakdown of family life, the parents concerned bear a heavy responsibility for the damage that accrues to their children.<sup>62</sup>

Responsibility in this statement not only implies that parents will help their children, but also that this is, in part, because parents feel guilty, or responsible, for their child's mental handicap.

Morris' comments were part of a debate on whether the responsibility for mentally handicapped children should be moved from the Ministry of Health to the Department of Education and Science. In 1968 Segal persuaded the government to transfer responsibility for mental handicap from the Ministry of Health to the

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<sup>61</sup> *Hansard's Parliamentary Debates*, 13 July 1966, vol. 276, cols 117-96.

<sup>62</sup> *Hansard's Parliamentary Debates*, 18 February 1966, vol. 724, cols 1707-91.

Department of Education and Science.<sup>63</sup> As such, the education of mentally handicapped children was reconsidered under the Education (Handicapped Children) Act of 1970.<sup>64</sup> Segal was in favour of community care, but chaired Rescare, an organisation which opposed the run-down and closure of long-stay institutions. The 1970 Education Act stated that no child was incapable of education and promoted the closure of traditional, long-stay institutions. As such the Act corresponded with the normalisation agenda which had come to prominence in Britain towards the end of the 1960s, in part due to the work of the NSMHC.<sup>65</sup> When the Bill was passing through the House of Lords, Lord Stonham acknowledged the role played by the NSMHC: 'It is only due to the work of the National Society for Mentally Handicapped Children that the authorities . . . have come to accept this fact and begun to do something to put it right.'<sup>66</sup> Lord Raglan also acknowledged the role of the NSMHC in the new legislation:

parental stigma is steadily disappearing; and it is this new attitude—the realisation that mentally disabled children are not children to be ashamed of and locked away, but are to be [*sic*] treated like all other children and drawn as much as possible into the normal life of the community—that has led at last to the transfer of responsibility for their education from the Department of Health to the Department of Education.<sup>67</sup>

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<sup>63</sup> In 1968 the Ministry of Health became the Department of Health and Social Security.

<sup>64</sup> *Education (Handicapped Children) Act* (1970), Ch. 52.

<sup>65</sup> Borsay and Dale, 'Introduction', p. 11.

<sup>66</sup> *Hansard's Parliamentary Debates*, 21 July 1970, vol. 311, cols 910-36.

<sup>67</sup> *Hansard's Parliamentary Debates*, 7 April 1971, vol. 317, cols 327-402.

The December 1970 edition of *Parents' Voice* cautioned that 'it will be many years before the trained teachers, ancillary staff and adequate buildings are available in sufficient numbers to radically change the current situation.'<sup>68</sup> Despite growing interest in and recognition of the needs of mentally handicapped children at the end of the 1960s and the 1970s, the NSMHC did not rest on its laurels: 'In the localities as well as at the Centre, we must continue to think deeply on issues of policy and make our views known on behalf of these young people who cannot speak for themselves.'<sup>69</sup>

In the wake of the Ely Hospital scandal the NSHMC funded a study of institutions for the mentally retarded. The report, entitled *Put Away* (1969), was written by Pauline Morris under the supervision of Peter Townsend who wrote a foreword to the book.<sup>70</sup> *Put Away* was reviewed widely in the press and on 12 July 1971 Morris' book was acknowledged by Labour MP Christopher Mayhew in a House of Commons debate on the Mentally Handicapped.<sup>71</sup> Morris found that homes, or hostels, were less isolated from the community than hospitals.<sup>72</sup> Also, 'information about families was normally much more readily available in homes than . . . hospitals' and that 'there also seemed to be much more visiting of patients by relatives than was the case for hospital patients.'<sup>73</sup> When parents visited children who had been admitted to hospitals with more than 1,800 beds, which were unlikely to have a Parents' Association: 'there appeared to be little or no attempt by

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<sup>68</sup> *Parents' Voice*, 20:4 (December 1970), p. 3, pp. 6-7.

<sup>69</sup> *Parents' Voice*, 19:3 (September 1969), p. 3.

<sup>70</sup> For more on the Ely Scandal and Peter Townsend see Chapter One of this thesis.

<sup>71</sup> *Parents' Voice*, 19:4 (December 1969), p. 4; *Hansard's Parliamentary Debates*, 12 July 1971, vol. 821, cols 35-98.

<sup>72</sup> Pauline Morris, *Put Away: Institutions for the Mentally Retarded* (New Brunswick and London, 1969), p. 261

<sup>73</sup> Morris, *Put Away*, pp. 269-70.



staff to take advantage of such visits to learn more about their patients, nor to try and encourage the relatives to be more involved in the process of training and social integration.<sup>74</sup>

During a three-day conference following the publication of *Put Away*, the General Secretary of the NSMHC, G.W. Lees, stressed that 'between 40 and 60 per cent of those in hospitals today were capable of living outside in the community' and he said that it was "a quite monstrous thing" to contemplate similar cases being admitted in future because there was no alternative place for them to go.<sup>75</sup> Pauline Morris stressed, however, that 'this did not mean that parents of mentally handicapped children should be expected to care for them forever. . . It was not realistic to think that parents growing older should have to care indefinitely for their mentally handicapped adult children.'<sup>76</sup> In 1971 the findings of an inquiry into the conditions of long-stay institutions, triggered in part by the findings of *Put Away*, and also by *Sans Everything*, was published in the white paper *Better Services for the Mentally Handicapped*.<sup>77</sup> In response to the white paper, The Campaign for the Mentally Handicapped emerged which produced pamphlets to educate and inform the public whilst fighting injustice.<sup>78</sup> The NSMHC broadly welcomed the white paper as 'sensitive, visionary, and hopeful' but noted that 'MOST OF IT HAS BEEN SAID BEFORE, BY PARENTS, OVER THE YEARS – AND NO ONE HAS NOTICED.'<sup>79</sup>

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<sup>74</sup> *Parents' Voice*, 19:4 (December 1969), p. 4.

<sup>75</sup> G.W. Lees previously worked for British Council for Rehabilitation and the Disabled and Save the Children: *Parents' Voice*, 21:1 (March 1971), p. 8.

<sup>76</sup> *Parents' Voice*, 20:1 (March 1970), pp. 8-14.

<sup>77</sup> For an examination of *Better Services for the Mentally Handicapped* (1971) and *Sans Everything* see the Chapter One of this thesis.

<sup>78</sup> *Hansard's Parliamentary Debates*, 12 July 1971, vol. 821, cols 35-98.

<sup>79</sup> *Parents' Voice*, 21:3 (September 1971), 3.

*Put Away* was critiqued in the December 1969 edition of *Parents' Voice* for giving little recognition to Friends' groups visiting "'unvisited" patients in the wards'. The critique also mentioned that some children ended up in hospital because of advice given to parents by medical professionals, and due to a lack of professional support within the community which would have helped give parents 'the health, strength or ability to look after grievously subnormal children at home' and thus saved them 'the pain of fruitless visits.'<sup>80</sup> Parents wrote in to *Parents' Voice* to express their frustration at inadequate service provision, suggesting that old age was not the only barrier to parental care-giving. The mother of an autistic eight-year-old boy wanted him to attend a school for autistics, but he was offered a place in a mental hospital instead. The family decided to 'bring him home again as we feared that whatever intelligence and good points he had would have been suppressed in such conditions. He was currently attending a training centre where his needs are not at all catered for.'<sup>81</sup>

During the 1970s, however, the NSMHC continued to support the training of parents so that they could provide effective care for their children at home. The March 1971 edition of *Parents' Voice* launched a new feature called 'Talking to Parents' which provided information from experts on day-to-day problems, including 'persuading the infant to accept food from a spoon'.<sup>82</sup> Although handicapped children were granted better access to education following the 1970 Education Act, early-years training by parents was still vital. Margaret Thatcher, the Secretary of State for Education and Science, stated: 'there is no doubt that many

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<sup>80</sup> *Parents' Voice*, 19:4 (December 1969), pp. 20-21.

<sup>81</sup> *Ibid.*, p. 29.

<sup>82</sup> *Parents' Voice*, 21:1 (March 1971), p. 14.

[handicapped children] can, with good care and training, live useful and contented lives, and find satisfaction in gainful employment.’<sup>83</sup>

When the NSMHC celebrated its Silver Jubilee in 1971, Sir Keith Joseph, Secretary of State for Social Services, reflected that: ‘the Society has grown from a small group of parents to a leading national voluntary organisation. . . it has been of immense help to the mentally handicapped and their families.’<sup>84</sup> Judy Fryd, also reflected on the achievements of the NSMHC, but indicated that further changes needed to occur:

There is no contradiction between asking for special help for mothers with the heavy burden of a mentally handicapped child at home, and the desire for these mothers to participate in all the amenities of community life and not to be perpetual, *unpaid nurses* with no time off, no relief, and no freedom to live their own life when their children are grown up. Parents, too, are people.<sup>85</sup>

Irene Nuttall, a speaker at the 1974 NSMHC Convention, described her experiences as the parent of a mentally handicapped child: ‘she spoke of the “snail’s pace at which these hostels are being built” and the assumption that parents would continue to look after and support their child indefinitely. Parents’ rights were all too often neglected.’ Nuttall wanted the Society to set up a counselling service, to settle the question of legal guardianship of adults with mental handicaps, and to ensure that *Better Services for the Mentally Handicapped* was implemented. The NSMHC had already begun to campaign for rights. The 1973 campaign of the

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<sup>83</sup> *Parents’ Voice*, 21:2 (June 1971), pp. 4-5.

<sup>84</sup> *Parents’ Voice*, 21:4 (December 1971), p. 5.

<sup>85</sup> *Ibid.*, pp. 6-7.

NSMHC was called 'I am your countryman. Stand up for my rights'. Now that the mentally handicapped had begun to be accepted into society, it was the new focus of the Society to fight for their rights.<sup>86</sup>

In March 1975 the NSMHC published a special edition of *Parents Voice, Help for Parents*, which discussed service provision for families and called for experts to listen to relatives more. An Editorial by Joyce McCarthy, the East Midland Regional Officer, stated: 'improved communication with the needs of families with a mentally handicapped member would prevent crisis situations and relieve pressure on the social workers.'<sup>87</sup> Peter Mittler, of the University of Manchester, discussed parental involvement:

The lack of effective help and services for parents of handicapped children constitutes one of the weakest features of our services, and one of our aims in the coming decade must be to find means of helping parents to work in closer partnership with professionals. Parents are the key figures in the development of the child. They are the only real experts, and yet they complain bitterly that their knowledge of the child is not actively sought by professionals . . . Parents of handicapped children have special needs and difficulties.<sup>88</sup>

A year later, in March 1976, the NSMHC published another special issue of *Parents Voice*, entitled 'Focus on the Family'. The editorial described some of the problems faced by families, including high instances of divorce, and feelings of isolation, stigma, and guilt. The issue predominantly consisted of personal accounts

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<sup>86</sup> *Parents Voice*, 24:2 (June 1974), p. 5; *Parents Voice*, 23:1 (March 1973), p. 3.

<sup>87</sup> *Parents Voice: Help for Parents*, 25:1 (March 1975), p. 3.

<sup>88</sup> *Ibid.*, pp. 5-7.

from families with a handicapped child but 'the picture that emerges is not of a shattered family but of a determination to keep family life as normal as possible whatever the problems'. The journal recommended that 'a network of services which take into account the needs of the "*whole*" family are the right of every family with a mentally handicapped child.' The services suggested were 'short-term care during family crises or holidays, counselling and welfare services . . . [and] parent training groups'.<sup>89</sup> This was part of a broader shift in awareness at the time of the impact of handicaps on relatives. Indeed, such awareness encouraged some to talk of the 'handicapped family.' In 1972, for instance, MP Alf Morris, who became the world's first Minister for the Disabled in 1974, stated that 'by definition of the word "family", if one member of the family is disabled the family as a whole is disabled.'<sup>90</sup>

The Report of the Committee of Enquiry into the Education of Handicapped Children and Young People, also known as the Warnock Report, was published in 1978. The report was welcomed by the NSMHC as a 'blueprint for change, and change for the better', especially in relation to its move towards inclusion of mentally handicapped children in mainstream education and "'the central place of parents in our view of special education.'" The NSHMC, however, was keen 'to press the local authorities to take action'.<sup>91</sup> Journalism academic and Fabian Society member, Walter Jaehnig hypothesised in 1979 on why mental handicap was often overlooked: 'as long as mentally handicapped people are living with their families - or elsewhere in the community - they are a low priority group.' He also stated that

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<sup>89</sup> *Parents Voice: Focus on the Family*, 26:1 (March 1976), p. 3.

<sup>90</sup> *Hansard's Parliamentary Debates*, 29 November 1972, vol. 847, cols 432-510.

<sup>91</sup> *Parents Voice*, 28:3 (September 1978), p. 3.

'80 per cent of handicapped children and 40 per cent of handicapped adults live in their family homes.'<sup>92</sup> Jaehnig's comments suggest that whilst families cared for mentally handicapped relatives in the home, improved service provision for this group would not be a priority. Researchers from Bristol University, Diana Pomeroy, Jane Fewtrell, Margaret Adams, Neville Butler and Roger Gill, shared similar concerns, noting in *Parents Voice* that: 'inadequate support for families looking after a severely mentally handicapped child at home might result in the breakdown of the family unit.' They based their assertion on a survey of 'the everyday family lives of families with a severely handicapped member.'<sup>93</sup> By the end of the 1970s the NSMHC was becoming interested in the ways parents and professionals could work together in partnerships.<sup>94</sup> 'It is for us to ensure that our voice is never a whisper. It is up to each and everyone one of us to speak, sometimes to shout and scream if necessary.'<sup>95</sup>

In conclusion, between the late 1950s and the 1970s educational opportunities for mentally handicapped children began to change with the widespread adoption of the normalisation agenda. The NSMHC, having gained a foothold in Parliament and boasting members from various related professions, was able to play a significant role in this change, not least by setting up work and rehabilitation schemes. Between 1946 and 1979, the education of handicapped children had changed from mothers, like Judy Fryd, educating children informally at home, to some of these children being able to attend mainstream schools. This

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<sup>92</sup> Walter B. Jaehnig, *A Family Service for the Mentally Handicapped* (London, 1979), p. 15.

<sup>93</sup> *Parents Voice*, 28:4, (December 1978), pp. 4-5.

<sup>94</sup> *Parents Voice*, 29:2 (June 1979); *Parents Voice*, 30:1 (March 1980), pp. 14-15. In 1980 the NSMHC became the National Society for Mentally Handicapped Children and Adults.

<sup>95</sup> *Parents Voice*, 30:1 (March 1980), p. 3.

change took some of the pressure away from parents and gave them hope that their children might be able to achieve a degree of independence in adulthood. Parents, including members of the NSMHC, were not only fulfilling the role of carers for their mentally handicapped children but they also campaigned for their children to have better access to medical services and educational opportunities, advancing the notion that they were experts of the needs of their own children in particular. Parents were demanding to have a say in the care and education of their children.

### **Respite for Carers: Mencap, c. 1981-1996**

The 1981 Education Act enabled mentally handicapped children to access mainstream education. Mencap supported the Act, not least because it required local maternity and paediatric hospital units to 'put families of babies diagnosed as mentally handicapped in touch with local branches of Mencap, so we can offer them the support of parents whose empathy and experience can give comfort and hope at that traumatic time.'<sup>96</sup>

The Winter 1985 edition of *Parents Voice* reflected on Mencap's progress thus far. Mentally handicapped children were now able to access full-time education, which meant that 'it was [no longer] left to parents to provide their own help and support.' Also, 'parents, through MENCAP, have shown that not only are

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<sup>96</sup> *Parents Voice*, 36 (Spring 1986), p. 5.

people with mental handicap educable, they are capable of contributing to the community through their skills and enthusiasm as employees.'<sup>97</sup>

Access to mainstream education was by no means guaranteed for children with learning disabilities by the mid-1980s. This led some parents to form grass-roots organisations to petition local authorities and schools to make integration a reality. One such group was SPINN, the Newham Support Network for Parents of Children with Disabilities, which 'hoped that the 1981 Act might mean children being seen as individuals rather than medical specimens.'<sup>98</sup> As supporters of the social model of disability, these parent activists adopted a human rights approach and later supported the notion of inclusion, which supported the mainstreaming of people with disabilities rather than expecting them to receive a special education.

National Mencap adopted a less activist approach and the organisation was openly critical of 'normalisation'. 'We each have our own individual needs and this includes people with mental handicap who require a "choice" of community-care services, the same way that other citizens are given a variety of opportunities.'<sup>99</sup>

The individuality of handicapped children and their families is evident in the story of Pat Firby and her son Paul. Although she cared for Paul throughout his childhood, when he reached adolescence, Pat began to struggle: 'to get him ready for the bath or take him to the toilet took every ounce of strength, as well as infinite patience.' After spending time in a hospital for the mentally handicapped, Pat was moved to Cleveland Social Services Hostel where he was much happier and "'doing more for himself'". '[Pat] is now able to enjoy life to the full, participating once more in the

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<sup>97</sup> *Parents Voice*, 35:4 (Winter 1985), p. 3.

<sup>98</sup> Linda Jordon and Chris Goodey, *Human Rights and School Change: The Newham Story* (2nd edn, Bristol, 2002), pp. 12-13.

<sup>99</sup> *Parents Voice*, 35:4 (Winter 1985), p. 3.



world outside', but she wished Paul had had 'regular spells of short-term care' earlier on to make it less "traumatic" when they reached "breaking point" and she had to "let go".<sup>100</sup> This sentiment was shared by Brian Rix, Secretary General of MENCAP:

parents realise that for a person with mental handicap to move away from the family home and live in a house in the neighbourhood can only loosen the ties in the best possible way, so that when the parents do eventually die, the mentally handicapped adult is not left in a complete state of isolation.<sup>101</sup>

Also in 1986, *Parents Voice* discussed independent living for those with mental handicaps, asking, 'should a move from home take place *before* we die or can no longer cope?'<sup>102</sup>

One of the first British learning disability self-advocacy groups, People First London, was founded in 1984. People First London was set-up by a group of British delegates who attended a self-advocacy meeting in the USA. By the 1990s, the self-advocacy movement for learning disability became more popular leading some to criticise organisations, including Mencap, which had originally been set up as parents' organisations. The disability rights movement came to prominence in the 1960s, but the learning disability rights movement did not emerge until later. As argued by health and social care academic Dorothy Atkinson, self-advocacy groups

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<sup>100</sup> *Parents Voice*, 35:2 (Summer 1985), pp. 8-9.

<sup>101</sup> *Parents Voice*, 36 (Spring 1986), p. 15.

<sup>102</sup> *Parents Voice*, 36:4 (Winter 1986), pp. 9-13.

for learning disability emerged in Sweden and the USA by the late 1960s, but were slower to emerge in Britain.<sup>103</sup>

Learning disability academics Barry Gray and Robin Jackson have argued that Mencap experienced conflicts of interest because of its roles as a campaign organisation, an advocacy group, and a service provider. Another source of conflict related to whether groups were run *by* disabled people, rather than, run *for* disabled people, like Mencap.<sup>104</sup> Another concern was changing terminology. In early 1991, Rix made a stand against moves away from old labels: 'My daughter is mentally and physically handicapped. To say she has "learning difficulties", as some would like, is just nonsense.'<sup>105</sup> In July 1991, however, another issue of *Mencap News* employed the term 'learning difficulties' and provided information about People First: 'historically, people with learning difficulties have always had others to speak for them, but that is changing, and it is one of the most exciting developments happening in the world today.'<sup>106</sup>

In 1991 Rix voiced concern that few young parents were joining Mencap:

On the whole they do not turn to us until their children grow up; they appear to feel that school meets all their needs. But by joining a local society these parents would - or should - get particular encouragement and support at an early stage from people who have been through it.<sup>107</sup>

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<sup>103</sup> Dorothy Atkinson, *Advocacy: A Review* (Brighton, 1999), p. 123.

<sup>104</sup> Atkinson, *Advocacy*, pp. 11-12.

<sup>105</sup> *Mencap News: Incorporating Parents Voice*, 9 (January/February 1991), p. 2.

<sup>106</sup> *Mencap News: Incorporating Parents Voice*, 14 (July 1991), pp. 4-5.

<sup>107</sup> *Mencap News: Incorporating Parents Voice*, 9 (January/February 1991), p. 2.

The following year, in 1992, Mencap was re-launched to attract new membership and reconfigure its aims, with a reorientation towards self-advocacy.<sup>108</sup> However, one of the six manifesto points, set out by Mencap concerned family life:

Today, thanks to medical science many people with a learning disability outlive their parents but they do not develop their own independence. MENCAP is battling to give these parents an appropriate level of government support which is equal to that given to children in their dependent years . . . Respite care is at the top of MENCAP's agenda. According to an Office of Population Census and Surveys (OPCS) survey, only 17 per cent of all children with severe learning disabilities get any respite care at all while the figure is even lower among adults. . . across Britain the provision for respite care is diminishing rather than increasing.<sup>109</sup>

Following the re-launch, *Mencap News* began to include a campaigns pull-out section, updating members on the campaigning efforts of the organisation. Mencap Chairman, Brian Rix, whose daughter had Down's Syndrome, became a life peer on 27 January 1992 and campaigned for the rights of people with learning disabilities and their carers in both the House of Lords and as part of the All-Party Disablement Group with Lord Renton, Lord Ashley, and Alf Morris. On 25 February 1993 Lord Ashley introduced a debate on carers by asking the government 'what action they are taking to deal with the financial, physical and emotional problems of carers' of which there were 'an estimated 6.8 million . . . in the United Kingdom, 1 million of whom provide care or assistance for at least 35 hours a week.' Ashley

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<sup>108</sup> *Mencap News*, 41 (January/February 1994).

<sup>109</sup> *Mencap News*, 29 (November 1992), pp. 12- 13.

stated that 'carers do not only suffer poverty; they also suffer lost opportunities.'<sup>110</sup>

Lord Rix's contribution focused on the need for residential care for adults with severe learning disabilities to improve the lot of 'those elderly parents trapped into providing care that they are increasingly less able to deliver . . . [and] denied the chance to have their own increasing needs met because they must give priority to a son or daughter still totally dependent on them.' Rix also defended the use of the term 'carer', a term deplored by some disability rights activists: 'I shall not apologise for using the term "carer", although I understand that "care" and "carer" are frowned on in rather more radical circles.'<sup>111</sup>

The October/November 1994 edition of *Mencap News* was a 'Families: Special Issue', borne out of concern for a lack of interest in the International Year of the Family in the UK and concern that, as learning disability self-advocacy groups emerged, people with learning disabilities would distance themselves from Mencap. As such it was stressed that 'Mencap represents, and should be concerned with, the happiness and welfare of all members of the family.'<sup>112</sup> The rest of the edition comprised of families' experiences and considered ways in which services for families could be improved.

Another concern for Mencap was that government promises for community care had not been fulfilled. On 17 July 1990, Mencap's parliamentary assistant Mary Holland wrote to Shadow Minister for the Disabled Alf Morris stating:

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<sup>110</sup> *Hansard's Parliamentary Debates*, 25 January 1993, vol. 543, cols 388-410.

<sup>111</sup> *Ibid.*

<sup>112</sup> *Mencap News*, 48 (October/November 1994), p. 1.

Society places a tremendous burden on families, and in return provides little financial, physical and social support. Assessment of individuals' needs, and support and services to meet them are essential if people with mental handicap and their families are to have the independence, freedom and choice which the government insists underpin their policies.<sup>113</sup>

Assessment of needs and service provision remained a concern for Mencap and in June 1995 the results of interviews and questionnaires conducted with principal officers and care managers, people with learning disabilities, and carers were published. The report concluded that following The National Health and Community Care Act (1990) 'people with learning disability have received relatively little attention' in comparison to other people with special needs, including the mentally ill. The survey found local authorities were 'failing to base care management and assessment procedures on the spirit and philosophy of the original legislation.'<sup>114</sup> In terms of carers, their needs were 'often ignored'.<sup>115</sup>

Four out of ten carers interviewed felt that their needs were not taken into consideration at all during the assessment; some believe that assessors 'only listened, it was lip service'; and a number said their views were only taken into account because they expressed their needs firmly.<sup>116</sup>

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<sup>113</sup> LSE Archives and Special Collections (LSEA), Morris, Alfred, MORRIS/1/15/5, Parliamentary Briefings, *Mary Holland*, *MENCAP* (17 July 1990), p.1.

<sup>114</sup> Peter Singh, *Community Care: Britain's Other Lottery. A Mencap Report on the Practice of Care Management and Assessment for People with Learning Disabilities* (London: Mencap, June 1995), pp. i-ii.

<sup>115</sup> *Ibid.*, p. iii.

<sup>116</sup> *Ibid.*, p. 25.

Rather than having their needs taken into consideration by professionals, carers were continuing to speak on behalf of their relatives with learning disabilities: 'many people with learning disabilities have greater need of advocacy than other people receiving a community care assessment. Carers can provide help in understanding and communicating needs'.<sup>117</sup> Mencap had campaigned for many years for parents, by this stage more frequently referred to under the umbrella term 'carers', to be taken seriously as medical and educational spokespeople for their relatives. By the mid-1990s carers were listened to by professionals, but the needs of carers themselves were often not discussed or were ignored.

In 1996 Lord Rix's Private Members Bill, Disabled Persons and Carers (Short-term Breaks) was discussed in the House of Lords. Rix asserted: 'existing legislation, including the new Carers Act, does not guarantee either assessment of the need or the provision of short-term breaks. This is an essential right if community care is to continue to function and to mean-primarily-family care.' The government did not feel that further legislation was necessary, however, with Baroness Miller of Hendon stating that 'the existing framework will undoubtedly work'.<sup>118</sup> Even though the Bill was not enacted, Rix and Mencap continued to campaign for the needs of carers. By the mid-1990s, Mencap conceptualised the needs of disabled persons and carers as being different but connected. Rix was seeking 'to give ordinary people with special needs and special responsibilities more ordinary lives'.<sup>119</sup> Mencap included people with learning disabilities and family carers within the broader category of 'disabled people and carers'. Mencap was hoping to ensure

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<sup>117</sup> Ibid., p. 26.

<sup>118</sup> *Hansard's Parliamentary Debates*, 17 April 1996, vol. 571, cols 751-82.

<sup>119</sup> Ibid.

that the needs of people with learning disability would no longer be overlooked in discussions regarding community care, and also to overcome criticisms from the self-advocacy movement.

In conclusion, during the period from the 1980s until the mid-1990s Mencap continued to campaign to improve the lives of people with learning disabilities and their family carers. Mencap was keen for the needs of people with learning disability and their carers to be considered in decisions about community care, especially regarding adults with learning disabilities and their elderly carers. With the emergence of the learning disability self-advocacy movement, Mencap worked to maintain its relevance and therefore became more concerned with the civil rights of people with learning disabilities. This led to potential conflict with Mencap's longer-term support of parents speaking on behalf of their children with learning disabilities. Mencap began to refer to parents as carers for the first time and made it a priority to extend the respite care available to this group both by providing their own services and by lobbying Parliament.

## **Conclusions**

This chapter has examined the ways in which the case study of Mencap can inform our understanding of the history of the emergence of the category of the family carer from the mid-1940s onwards. As the first parents' group for mental handicap, Mencap was influential in terms of advising parents, setting up services, and successfully lobbying Parliament. The NAPBC emerged when parents of mentally

handicapped children were increasingly expected to provide care for their relatives in the home because of three main factors: long waiting lists for institutions; the 1944 Education Act, which deemed mentally handicapped children 'ineducable'; and new child development theories, which recognised the important role of mothers in their child's early-years. The NAPBC encouraged parents to care for their mentally handicapped children at home, but also to train and educate them.

From the mid-1950s, the NSMHC was able to become influential in Parliament, initially by giving evidence for the 1954-57 Royal Commission and later establishing Parliamentary officers, and garnering the support of MPs and Peers. This helped to ensure that all children were deemed capable of an education under the 1970 Education Act. Rather than focusing on the caring role of parents, the NSMHC encouraged parents to provide training for and to speak on behalf of their children. Parents were empowered to push for access to the services they wanted for their children and the NSMHC wanted the views of parents to be taken seriously by professionals. In 1992 Mencap made it a priority to relieve the burden of care placed on families by caring for children with learning disabilities. The organisation campaigned for family carers to have better access to individual carer needs assessments and respite care. A particular concern was parents of adult children with learning disabilities and what would happen when the parents were no longer able to care. Mencap was able to continue having its voice heard by using the rhetoric of 'disabled person and carer'. The activities of Mencap from 1946 onwards had contributed to the emergence of the category of the carer for learning disability, but it was not until the 1990s when carer legislation was being considered by Parliament that the organisation explicitly referred to its members as



carers. Mencap wanted the role of parents and families of people with learning disability to be conceptualised in the same way as family carers of other groups of individuals, including the mentally ill. During the 1990s, Mencap was criticised for primarily supporting the rights of carers, which were sometimes at odds with the rights of people with learning disabilities. This led Mencap to become interested in supporting, and extending, the rights of both carers and people with learning disabilities.

# 5.

## **The National Schizophrenia Fellowship and the Family Carer, c. 1971-1999**

This chapter examines the case study of the National Schizophrenia Fellowship (NSF) from its inception in 1971 until the formation of the Mental Health Alliance and the publication of the white paper *Caring about Carers: a National Strategy for Carers*, and the National Service Framework for Mental Health, all in 1999. The NSF has been selected as a case study because, it was one of the first notable parent non-governmental organisations (NGO) in the field of psychiatry. Further, the NSF constituted the largest group of carers for severe mental illness in England with 8000 members by 1995, most of whom were carers.<sup>1</sup> The NSF was founded by John Pringle, over twenty years after the NAPBC in 1971. The organisation changed its operating name to Rethink or Rethink Severe Mental Illness in 2002 and Rethink Mental Illness in 2011. As with mental handicap in the mid-1940s, by the early 1970s the parents and family carers of those with schizophrenia had cause to

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<sup>1</sup> Gary Hogman and Guy Pearson, *The Silent Partners: The Needs and Experiences of People who Provide Informal Care to People with Severe Mental Illness. An Overview of the NSF Survey into Carers' Needs* (Kingston Upon Thames, 1995), p. 8.

collectivise, in this instance in response to moves towards a policy of community care. By the early 1970s schizophrenia, with its unknown aetiology, was a particularly widely discussed, researched, and politically charged issue. The NSF's founding members were concerned that large-scale deinstitutionalisation would lead to a service gap with individuals diagnosed with schizophrenia given less support by the state and with more of a burden being placed on their family members, especially their parents.

This chapter predominantly examines the NSF with specific focus on two of its activities: its campaign for mental health service provision to be improved; and its work to raise the profile, and provide a voice for, families with a relative who had schizophrenia. Firstly, I outline the early years of the NSF from its inception in 1971 by journalist John Pringle to the publication of the NSF's *Living with Schizophrenia: By the Relatives* in 1975. I demonstrate that the NSF was founded in response to moves towards deinstitutionalisation and the rise of anti-psychiatry. I show that from the outset the NSF encouraged its members to share their experiences of being the relative of someone with schizophrenia, contributing to the emerging category of the carer. Secondly, I examine the NSF's activities between the mid-1970s and mid-1980s, which focused on campaigning on behalf of relatives to halt the closure of long-stay mental hospitals, to temper the burden care of a schizophrenic relative placed on relatives, and to encourage medical professionals to afford relatives agency over their relatives' care. This section focuses on the NSF's adversarial relationship with MIND (previously the National Association of Mental Health), anti-psychiatry, and the service-user movement. Thirdly, I focus on the period from the mid-1980s to 1999 to explore the

continuance of the NSF's campaign for more extensive service provision. Here, I examine how the NSF responded to the recognition from social policy makers and service-user groups that carers had their own needs and were therefore entitled to their own rights. Once the needs and rights of both service-users and carers had been acknowledged by policy-makers, carer groups, and service-user groups in their own right, the NSF and MIND were able to campaign collaboratively for better mental health services.

I argue that from the outset the NSF was keen to reject the burden of care its members and other relatives were faced with as mental hospitals closed and as care *by* the community, or more likely, families, became a distinct possibility for some, and a reality for others. The activities of the NSF throughout the 1970s, 1980s, and 1990s, however, helped to shape the category of the carer as it became increasingly acknowledged, particularly as the NSF wanted relatives to be thought of as 'experts'.

### **The Early Years of the NSF, c. 1971-74**

John Pringle, who had an adolescent son with schizophrenia, wrote a letter to *The Times* published anonymously on 9 May 1970 in which he gave details of his personal experiences of struggling with his son's condition and his concern that the lack of community service provision would place the burden of care with relatives. Pringle began the letter by expressing concern over the misuse of the term schizophrenia which he felt was 'flung about today with flip facility, bobbing up in

films, television scripts, literary criticism, even political articles'. Pringle also referred to his personal experiences with his son, explaining how he struggled to cope with 'this strange, new member of the household'. Pringle outlined his concerns over the current state of mental health services, which he felt were suffering from a 'scandalous fragmentation of responsibility between local authorities and the hospital service'. He wrote: 'No social provision exists for them, so their future is bleak. As parents die off and other relatives find it impossible to cope, the inevitable trend is for them to drift downwards to the welfare state's bottomest sump.'<sup>2</sup> Pringle had 'expected smooth or angry denials from hospital board chairmen, administrators, psychiatrists. The actual reaction was more surprising – just nothing a silence'.<sup>3</sup> Instead, his letter led to some 400 replies from parents in a similar situation, a response which directly led to the inception of the NSF.

Pringle used the letter as an instrument to disseminate his view that the closure of mental hospitals and inadequate community care service provision was placing the burden of care for schizophrenia on family members who, in his view, could not or should not accept this situation passively. As a parent of a mentally ill adolescent, Pringle had the personal experience and knowledge to relate to a broader group of parents with children who had been diagnosed with schizophrenia. In addition, as a journalist, Pringle had the cultural capital, in the form of education along with professional expertise and contacts, to become an

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<sup>2</sup> John Pringle, 'A Case of Schizophrenia', *The Times*, 9 May 1970, p. 9.

<sup>3</sup> PP/DSI/C/4/2, National Schizophrenia Fellowship Newsletter NSF News, 1980-1986, 'NSF News, April 1980', p. 1.

expert citizen.<sup>4</sup> Pringle was able to mobilise other parents to form a carer non-governmental organisation which aimed to provide mutual support and affect change.

The emergence of the NSF in the early 1970s was the product of broader developments in the mental health field during the late 1950s and 1960s, which gave Pringle's letter relevancy. Historian John Welshman has asserted that families were implicitly expected to become carers for their mentally ill relatives from the 1960s onwards, following the 1959 Mental Health Act and Enoch Powell's 1961 'Water Tower' speech. Sociologist David Skidmore has articulated this as 'care *by* the community, not *in* the community'.<sup>5</sup> With closures of long-stay mental hospitals and a shortage of hospital beds for the mentally ill, concern began to spread that with a lack of alternative, community-based service provision relatives would be expected to adopt a caring role. From the outset, John Pringle and the NSF membership, which was predominantly a middle-class organisation, actively sought to resist and challenge this perceived shift, keen to maintain familial rights over their relatives' treatment and to reject what they termed the 'burden of care' for schizophrenia.<sup>6</sup> This resistance, which will be examined in more detail later in this

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<sup>4</sup> For cultural capital, see: Pierre Bourdieu, 'The Forms of Capital' in Richardson (ed.), *Handbook of Theory and Research for the Sociology of Education* (Westport, 1986), pp. 234-44. For the expert citizen, see: Matthew Hilton, James McKay, Nicholas Crowson and Jean-François Mouhot, "'The Big Society': Civic Participation and the State in Modern Britain', *History and Policy* (June 2010), p. 7.

<sup>5</sup> David Skidmore, *The Ideology of Community Care* (London, 1994), p. xii; John Welshman, 'Rhetoric and Reality. Community Care in England and Wales, 1948-74', in Peter Bartlett and David Wright (eds), *Outside the Walls of the Asylum: The History of Community Care, 1750-2000* (London and New Brunswick, 1999), p. 226.

<sup>6</sup> The Wellcome Library, Dorothy Silberston, and the National Schizophrenia Fellowship, 1970-2004, WL, PP/DSI/C/1/3, National Schizophrenia Fellowship Publications 1970s-1980s, *Schizophrenia – the Family Burden* (1975), p. 2; John Pringle, 'Burden of Schizophrenia', *British Medical Journal*, 3:5933 (29 September 1974), pp. 700-01.

chapter, was a resistance to the emergence of the category of the carer, but, as I argue, the activities of the NSF also served to reinforce this categorisation.

The inception of the NSF followed the establishment of the National Society for Autistic Children (later The Autism Society) in 1968, another parent and carer group related to the field of psychiatry.<sup>7</sup> That the first parent and carer groups in the field of psychiatry were for autism and schizophrenia is unsurprising given the unknown nature of these conditions which created a space for theories about the pathogenic capacity of the family. Schizophrenia had no clear aetiology, it could be both an acute and a chronic condition which had varying degrees of severity. Further, schizophrenia had a long-standing association with the family and only presented itself during adolescence. Whilst those diagnosed with schizophrenia were capable of working they found it difficult to hold down jobs because of the unpredictable nature of the condition.<sup>8</sup> Historian Bonnie Evans has used the case study of autism to argue that the closure of long stay mental deficiency institutions led to a growing awareness, and diagnosis of, autism.<sup>9</sup> The same could be argued for schizophrenia, and as such it is unsurprising that parent and carer organisations for autism and schizophrenia emerged at the same time as mental and mental deficiency hospitals began to close.

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<sup>7</sup> Bonnie Evans, 'How Autism became Autism: The Radical Transformation of a Central Concept of Child Development in Britain', *History of the Human Sciences*, 26:3 (2013), pp. 3-31; Adam Feinstein, *A History of Autism: Conversations with the Pioneers* (Chichester, 2010); Ian Hacking, 'Autistic Autobiography', *Philosophical Transactions of the Royal Society*, 364 (2009), pp. 1467-73; Ian Hacking, 'How We Have Been Learning to Talk About Autism: A Role for Stories', *Metaphilosophy*, 40:3-4 (2009), pp. 499-516.

<sup>8</sup> Peter Barham, *Closing the Asylum: The Mental Patient in Modern Society* (London, 1992), p. 16; Peter Bartlett and David Wright, 'Community Care and its Antecedents', in Peter Bartlett and David Wright (eds), *Outside the Walls of the Asylum*, p. 4, pp. 14-6; Charles Anthony Butterworth and David Skidmore, *Caring for the Mentally Ill in the Community* (London, 1981), p. 42-44; Lucy Johnstone, *Users and Abusers of Psychiatry: A Critical Look at Traditional Psychiatric Practice* (London, 1989), p. 83, pp. 34-5; Welshman, 'Rhetoric', p. 226.

<sup>9</sup> Bonnie Evans, Bonnie Evans, 'How Autism became Autism: The Radical Transformation of a Central Concept of Child Development in Britain', *History of the Human Sciences*, 26:3 (2013), pp. 3-31.

The therapeutic optimism of the traditional psychiatric professionals, particularly prevalent during the 1940s and 1950s, lent itself to a psychical, biomedical view of mental illness with a tendency towards cure and physical treatments including newly developed psychotropic drugs and older methods including electro-convulsive therapy.<sup>10</sup> As psychologist and historian Peter Barham and others have noted, the need for life-long support for some patients was overlooked because of a preoccupation with a medical model that assumed an acute natural history of mental illness and focused on physical cure rather than social recovery.<sup>11</sup> Moreover, its focus was on the 'treatable borderlines', rather than chronic patients including those diagnosed with schizophrenia.<sup>12</sup> Without the 'safety valve' of institutional care, families were often left to cope without respite.

The inception of the NSF, then, should be seen as part of a broader move towards a social view of mental illness during the 1970s, which although not mutually exclusive from traditional, physical understandings, began to consider the patient's environment including their family life.<sup>13</sup> For social psychiatrists, anti-psychiatrists, and non-medical mental health professionals, including social workers, who were interested in the relationship between mental illness and the social, schizophrenia was an ideal case study for research. The unknown aetiology of schizophrenia also created a space in which the groups, and individuals within these groups, could debate and disagree with one another. The NSF did not

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<sup>10</sup> Vicky Long, "'Often there is a Good Deal to be Done, But Socially Rather Than Medically'". The Psychiatric Social Worker as Social Therapist, 1945-70', *Medical History*, 55 (2011), p. 228, p. 238; Roy Porter, 'Two Cheers for Psychiatry!' in Hugh Freeman and German Berrios (eds), *150 Years of Psychiatry: The Aftermath* (London, 1996), p. 400.

<sup>11</sup> Barham, *Closing*, pp. 13-14; Long, 'Social Therapist', p. 229; Barbara Taylor, 'The Demise of the Asylum in Late Twentieth-Century Britain: A Personal History', *Transactions of the Royal Historical Society*, 6:21 (December 2011), p. 200.

<sup>12</sup> Long, 'Social Therapist', p. 238; Porter, 'Two Cheers!', p. 396, p. 401.

<sup>13</sup> Long, 'Social Therapist', pp. 231-37.



explicitly favour either a social or a physical model of mental illness, instead lending their support to professionals from both approaches so as to maintain a united membership and to move towards a greater understanding of schizophrenia as a condition.<sup>14</sup> Regardless of this, the NSF was formed and came to be positioned in direct opposition to the view expressed by some, and in particular those associated with anti-psychiatry, that parents were to blame for schizophrenia.<sup>15</sup>

The first meeting of what was to become the NSF took place on 25 July 1970 at the Wellcome Foundation in London and was attended by fifteen people, from six families from across the country, who had been invited by Pringle from those that sent him correspondence following his letter to *The Times*.<sup>16</sup> After issuing a number of pamphlets and gauging the extent of public support for the cause with a survey in the press, which received 500 replies, the Fellowship had attracted a membership of 240 by the start of 1973, rising to 300 by November of the same year.<sup>17</sup> At the inaugural meeting of the NSF, attended by 140 members and held in London on 18 June 1974, the aims of the group were set out as being to help those with schizophrenia and their relatives, in part by drawing upon the knowledge and experiences of relatives as a resource to ensure that adequate knowledge about

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<sup>14</sup> WL, PP/DSI/B/2, Miscellaneous National Schizophrenia Fellowship Policy Papers, 1970-2001, *The Problem before us – some tentative thoughts*, p. 3.

<sup>15</sup> Nick Crossley, 'The Field of Psychiatric Contention in the UK, 1960-2000, *Social Science and Medicine*, 62:3 (2006), p. 556. Nick Crossley categorises the NSF as being part of an 'anti-anti-psychiatry movement', see: Nick Crossley, *Contesting Psychiatry: Social Movements in Mental Health* (London and New York, 2006), p. 5. For an examination of a broader critique of the family as pathological by contemporaries see: Roy Porter, 'Anti-Psychiatry and the Family: Taking the Long View', in Marijke Gijswijt-Hofstra and Roy Porter (eds), *Cultures of Psychiatry and Mental Health Care in Postwar Britain and The Netherlands* (Amsterdam, 1998), pp. 257-75.

<sup>16</sup> WL, PP/DSI/F/2, National Schizophrenia Fellowship History Booklet, *The Early Years: A History of the National Schizophrenia Fellowship (now Rethink)* (2004), pp. 7-8.

<sup>17</sup> WL, PP/DSI/F/2, *Early Years*, pp. 13-15.

and policies for schizophrenia were developed.<sup>18</sup> On 1 March 1982 the Council of Management of the NSF reflected on the core aims of the organisation from its inception and throughout its first ten years:

1. To influence government, parliament, and other authorities to make better public provision for schizophrenia sufferers and their families
2. To encourage and support financially research into the cause and better treatment of schizophrenia
3. To encourage and support publication of new knowledge about schizophrenia
4. To provide advisory services nationally
5. Last – but by no means least – to encourage and support self-help groups of sufferers and relatives.<sup>19</sup>

The NSF did not get the ear of Parliament straight away, but during the early years, the NSF did begin to conduct and disseminate research into relatives' experiences, produce pamphlets for educative purposes, and facilitate the emergence of local relative mutual support groups. In addition, the NSF's Medical Officer, social psychiatrist John Wing, published medical journal articles and advised Parliament on his research findings.<sup>20</sup> Wing asserted that the need for psychiatric hospital beds was likely to increase, not decrease, as social policy documents of the time, including the 1962 Hospital Plan, had indicated.<sup>21</sup> In line with the NSF's ethos, Wing stated that insufficient community-based provision for schizophrenia 'cannot

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<sup>18</sup> Ibid., pp. 15-16.

<sup>19</sup> WL, PP/DSI/A/3/1, AGM Minutes and Papers, 1979-2002, *AGM Minutes* (1 March 1982), p. 5.

<sup>20</sup> John Wing's influence on the medical community, social research, and social policy is explored in more detail in Chapter Two of this thesis.

<sup>21</sup> John Wing, 'How many Psychiatric Beds?', *Psychological Medicine*, 1:3 (1971), pp. 188-90.

prevent a considerable burden being placed on the health, leisure, and finances of families.<sup>122</sup>

The first local NSF branch was set up in the Midlands by Joy Major who had responded to Pringle's initial letter in *The Times* and attended the first meeting of what was to become the NSF. The group, which met for the first time on 25 October 1973, decided that their 'priority must be to establish credibility with the medical professionals.' Major has since reflected that during the early years the Midlands group 'focused on two things: first to bring relief to sufferers, second to establish a credible role for relatives as carers.'<sup>123</sup> It is unlikely that Major would have used the term carer itself during the early 1970s, as the term was not yet in widespread usage. Major's comment fits into the context of the NSF's desire to undermine the belief, propagated by those associated with anti-psychiatry, that parents were pathologically to blame for the onset of schizophrenia. Her statement, however, sits uncomfortably with Pringle's assertion that relatives should be able to reject the burden of care for schizophrenia and is an example of the paradoxical relationship between this and the NSF's other view that relatives should be taken seriously as 'experts' in the care of their family member with schizophrenia. The NSF wanted relatives to be able to choose whether they cared for their relative. But it also worked for the views of relatives to be afforded the respect of medical professionals.

In 1973 the NSF also published *Schizophrenia: The Family Burden*. Revised in 1974, the publication outlined the plight of families with a schizophrenic relative: 'The people who are not being heard are the families of schizophrenics, the people

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<sup>122</sup> Wing, 'Psychiatric Beds', p. 189.

<sup>123</sup> WL, PP/DSI/F/2, *Early Years*, pp. 19.

who really know what "community care" is and how ineffective it is at the present time.<sup>24</sup> The NSF encouraged relatives to share their experiences, which aside from providing mutual support for one another, was intended to raise the profile of these relatives and to spread awareness of their needs and experiences, and to form the basis of a critique of the current state of community care services.<sup>25</sup> Letters from relatives were frequently published in the Fellowship's newsletter, *NSF News*, and in 1974 the NSF published a compendium of relatives' letters entitled, *Living with Schizophrenia – by the Relatives*.<sup>26</sup> Relatives were encouraged to write down 'any personal experience [good or bad] which illustrates and illuminates what is wrong with present methods of "community care"'. Relatives who wrote to the Society, and supposedly also those who participated in mutual support groups, developed a shared discourse with similar experiences, and ways of expressing these experiences, recurring time and again. A common and recurrent theme was the expression of feelings of fear that following hospital closures families would be left with no option but to provide care in the home. The respondents expressed concern about the emotional impact this had, or would have, on the family: for instance, in terms of ageing parents, fathers who could not accept their child's diagnosis, and in response to the stigma associated with the condition.<sup>27</sup> The overall impression was that families wanted emotional support, but also pragmatic help and assistance in the form of mental health care services.

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<sup>24</sup> WL, PP/DSI/C/1/3, John Pringle, Schizophrenia: The Family Burden, National Schizophrenia Fellowship (1974), p. 4.

<sup>25</sup> WL, PP/DSI/C/4/1, National Schizophrenia Fellowship Newsletter and Magazine, 1973-2004, *NSF News* (June 1973), pp. 2-5.

<sup>26</sup> MRC, British Association of Social Workers, MMS.378/BASW/2/135, National Committee (Mental Health), *Living with Schizophrenia: By the Relatives*, National Schizophrenia Fellowship (1974).

<sup>27</sup> MRC, MMS.378/BASW/2/135, *Living with Schizophrenia*, p. 8, p. 11, p. 15, p. 27, p. 42.

As sociologist Deborah Lupton has argued, when a community of individuals share their emotions they follow a set of non-codified rules about what is and what is not acceptable to share.<sup>28</sup> Indeed, the NSF, and the NSF local mutual support groups, could be thought of as "emotional communities" with their own 'systems of feelings'.<sup>29</sup> The letters were also mediated by the NSF executive committee, who chose whether to include particular accounts in newsletters and publications. In this respect these written accounts may tell us more about the accepted shared experience of familial care of schizophrenia than about individuated experiences. Some relatives appear to have been empowered by their membership of the NSF and by sharing and expressing their emotions, becoming more assertive when interacting with medical professionals, including General Practitioners. NSF member Gretta Sherman 'felt as though [she] had jumped over a high fence and come down safely on the other side' when she mentioned to medical staff that she was part of the organisation. 'She said the atmosphere changed, and they all of them discussed her son's illness with her much more freely [and] they have agreed to keep him in hospital'.<sup>30</sup> The NSF hoped that these relatives would come to be recognised as primary care agents in the community, whilst also demonstrating that this was not a feasible model of mental health care as 'family relationships [were being] strained to the limit'.<sup>31</sup>

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<sup>28</sup> Deborah Lupton, *The Emotional Self: A Sociocultural Exploration* (London, 1998), pp. 18-19, pp. 170-71.

<sup>29</sup> Barbara H. Rosenwein, 'Worrying about Emotions in History', *American Historical Review*, 107:3 (2005), p. 284.

<sup>30</sup> WL, PP/DSI/C/4/1, *NSF News* (March 1975), pp. 5-6.

<sup>31</sup> WL, PP/DSI/C/1/17, National Schizophrenia Fellowship Publications, 1970s-1980s, *About Schizophrenia* (1985), p. 12.

One major reservation needs to be highlighted in any account of the role of the NSF in coming to represent the families of schizophrenic patients: the NSF was not a representative group. As Pringle explained in the preface to *Living with Schizophrenia*, 'these extracts [were] the products of an articulate minority' who had overcome the 'fear of taking action'.<sup>32</sup> As a predominately middle-class group, the NSF was conscious that it might not be representing the experiences of all familial carers of schizophrenia. To negate this bias the NSF commissioned an 'authoritative independent' survey by social psychiatrist and NSF medical officer John Wing and his colleague Clare Creer in 1974, entitled *Schizophrenia at Home*, which is examined in detail in Chapter Two of this thesis.

In conclusion, the NSF emerged in response to fears that the family would be burdened with the care of schizophrenia in the context of inadequate community care provision. The NSF was formed in opposition to those, often associated with anti-psychiatry, who thought the family were the cause of schizophrenia and who also tended to support the closure of mental hospitals. During the early years of the organisation the NSF concentrated on providing mutual support for caring relatives, disseminating relatives' experiences, and resisting the burden placed on families with a relative who had schizophrenia. Relatives of those with schizophrenia collectivised, at a time when a wide range of social movements were mobilising, to campaign for adequate social welfare provision for schizophrenia, to resist the burden of care placed on families by schizophrenia, and to be taken more seriously by medical professionals. By grouping together relatives, the NSF raised the profile of the role of families in

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<sup>32</sup> MRC, MMS.378/BASW/2/135, *Living with Schizophrenia*, p. 1.

mental health care provision and encouraged relatives to more strongly identify themselves as relatives of people with schizophrenia. Paradoxically the NSF contributed to, and helped to consolidate, the emergent category of the carer whilst also rejecting the basis of this categorisation. Although the NSF did not represent all families with relatives who had a diagnosis of schizophrenia the group was to become sizeable and influential enough to work towards achieving many of its aims via securing a platform with both professionals and the public.

### **The NSF and MIND, c. 1971-1987**

In terms of the emergence of the category of the carer, two of the NSF's core objectives, which also led to the group's adversarial relationship with MIND, are particularly relevant. Firstly, the NSF campaigned for better community care service provision for those with schizophrenia in order to reduce the burden of care placed on family members. The NSF also campaigned to halt the closure of mental hospitals until community services had been adequately established. Secondly, the NSF wanted relatives of those with schizophrenia to be considered as experts by medical professionals and supported the extension of the rights of the nearest relative within mental health legislation. The NSF wanted to support the well-being of relatives and wanted acknowledgement that schizophrenia affected the sufferer's wider family and thus that the family should have a say in their relatives' care and treatment. These two core objectives ensured that the NSF adopted an adversarial relationship with the National Association of Mental Health (NAMH),

which in 1972 changed its name to MIND. Initially, there was an important distinction in the interests of the two organisations. The NSF focused on supporting those with mental illness and their families, whilst the NAMH was concerned primarily with the promotion of mental health. Yet, the newly re-written aims of the NAMH now specifically included the objective of supporting the families of those with mental illness. This shift of interests may have contributed to tension with the NSF. However, more fundamentally, it was the sharp contrast in attitudes towards care for the mentally ill that divided the two. In particular, MIND was far more sympathetic towards the anti-psychiatry movement and it supported the interests of service-user organisations. For instance, it supported hospital closures and campaigned for the rights of service-users to be paramount in mental health legislation.

The tension that existed between service-user and carer organisations during the 1970s can be attributed to the conflicting interests of both parties and to conflicts over contemporary theories about the family. During the 1980s, this adversarial relationship continued as both parties attempted to raise their public profile and propagate their own view of mental health care.<sup>33</sup> As Sociologist Nick Crossley has suggested, organisations are defined, and define themselves, in relation to one another.<sup>34</sup> The NSF orientated itself in opposition to MIND's civil liberties-based approach, but engaged in the use of similar rights-based discourse. As sociologist Nick Crossley has argued, what he calls social movement

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<sup>33</sup> John Turner, Rhodri Hayward, Katherine Angel, K.W.M. Fulford, John Hall, Chris Millard and Mathew Thomson 'The History of Mental Health Services in Modern England: Practitioner Memories and the Direction of Future Research', *Medical History* (forthcoming).

<sup>34</sup> Crossley, *Contesting*, p. 191.



organisations are defined, and define themselves, in relation to one another.<sup>35</sup> The NSF promoted the conception of the families of those with schizophrenia as a distinct entity with distinct needs, at the same time as relatives were being thought of as carers in popular, political, and professional discourse.

Since the inter-war years, the mental hygiene movement had long been in favour of a move towards mental health rehabilitation and treatment in the community. The NAMH, which was formed in 1946 following the merger of three organisations associated with mental hygiene, also adopted this view.<sup>36</sup> Although the NAMH had reservations about whether community care provision would be adequate, the organisation had already pledged its support to the Bill that became the 1959 Mental Health Act, which is often noted by historians as a key turning point towards a government policy of community care.<sup>37</sup> However, as historian of social policy John Welshman has argued, the 1959 Act did not establish an explicit move towards community care, instead simply giving local authorities the power to set up more residential and training services for the mentally disordered in the community if they chose to.<sup>38</sup> However, in the early 1960s the government suggested that the 1959 Act did indeed support a move towards community care. And in the Minister for Health Enoch Powell's water tower speech of 1961 and the Mental Hospital Plan of 1962 details of hospital bed reductions and hospital closures for the mentally ill and mentally subnormal were outlined.<sup>39</sup>

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<sup>35</sup> Ibid., p. 191.

<sup>36</sup> Jonathan Toms, *Mental Hygiene and Psychiatry in Modern Britain* (Basingstoke, 2013), p. 182.

<sup>37</sup> Kathleen Jones, *A History of Mental Health Services* (London, 1972).

<sup>38</sup> John Welshman, 'Rhetoric and Reality: Community Care in England and Wales, 1948-74', in Peter Bartlett and David Wright (eds), *Outside the Walls of the Asylum: The History of Community Care, 1750-2000* (London and New Brunswick, 1999), pp. 210-11.

<sup>39</sup> Ibid., p. 211.

The closure of mental hospitals outlined in the 1961 speech and 1962 Plan was not, however, supported by everyone associated with the mental health field. In the following years a series of articles, published in notable journals the *Lancet* and the *British Medical Journal*, undermined the proposed hospital closures on the basis that sufferers of some conditions, including schizophrenia, required specialised in-patient care. The four psychiatrists who were to become the NSF's medical advisers, G.M. Carstairs, Donald Early, Henry Rollin, and John Wing, criticised the 1959 Mental Health Act on the basis that mental hospital closures, without adequate community-based provision, would result in inadequate provision.<sup>40</sup> In 1961, in his BBC Reith Lecture series *This Island Now*, Carstairs openly critiqued anti-psychiatry, a school of thought in favour of mental hospital closures. In the fourth lecture of the series Carstairs undermined anti-psychiatrist R.D. Laing and made a case for psychotic illness to be conceptualised as more than just a social phenomenon, and instead as an illness which required medical care:

Psychotic illness represents the complete breakdown of social functioning. It occurs when biological, social, and emotional events combine to make it impossible for an individual to maintain the coherence of his personality (and this happens to some people in every society).<sup>41</sup>

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<sup>40</sup> Vicky Long, 'Rethinking Post-War Mental Health Care: Industrial Therapy and the Chronic Mental Patient in Britain', *Social History of Medicine*, 26:4 (2013), p. 746.

<sup>41</sup> G.M. Carstairs, 'This Island Now: The Changing Role of Women' (1962) <[http://downloads.bbc.co.uk/rmhttp/radio4/transcripts/1962\\_reith4.pdf](http://downloads.bbc.co.uk/rmhttp/radio4/transcripts/1962_reith4.pdf)> (10 November 2014).

In opposition to anti-psychiatry, Carstairs, along with Early, Rollin, and Wing, were firmly in support of the notion that schizophrenia was a mental *illness*, which could not be fully explained via social explanations, including familial problems.

In 1971, the year the NSF was formed, the NAMH reformulated its aims under their newly launched MIND campaign. The seven main objectives of the campaign focused on decreasing stigma and improving understanding and treatment of those with a mental disorder. For the first time the NAMH adopted the specific aim of supporting the families of mental health patients (although the NSF would go on to dispute whether MIND delivered on this aim). The campaign, directed by former Secretary of Social Services David Ennals, sought to attract funding for the organisation and for the NAMH to become re-orientated as a lobby organisation. In 1972, following the success of the campaign, the NAMH was rebranded as MIND. In January 1974, shortly before Ennals was re-elected into Parliament in February, Tony Smythe was appointed director of MIND and tasked with incorporating the MIND campaign into the work of the organisation.<sup>42</sup> Tony Smythe, who had been appointed as head of the National Council for Civil Liberties in 1966, radicalised MIND as a pressure group with a rights-based approach.<sup>43</sup> Under Smythe's directorship, Larry Gostin a lawyer from the United States of America was appointed as MIND's first legal officer responsible for a new legal and rights advisory service. MIND was actively seeking to support and extend the rights of those diagnosed with mental illness, but in doing so it could be argued that the

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<sup>42</sup> Toms, *Mental Hygiene*, pp. 181-84.

<sup>43</sup> *Ibid.*, p. 181.

organisation not only undermined psychiatry and public confidence in the profession, but also perceptions of the relatives of those with mental illnesses.<sup>44</sup>

MIND took an approach which drew upon ideas associated with the mental hygiene movement, focusing not on mental *illness* but on the promotion of mental health. And this was now also inflected by the climate of anti-psychiatry, suggesting that not only was it important to move the focus of effort from mental illness to mental health, but also that the very notion of mental illness might be misconceived. In contrast, the NSF, and the medical advisors attached to the group, very much supported and promoted a focus on the needs of the mentally ill. With this in mind, the NSF campaigned to halt mental hospital closures and for patients' relatives to be viewed as primary care agents. The NSF was adamant in its opposition to the so-called anti-psychiatry movement and those, including MIND, who conceptualised schizophrenia as first and foremost a product of dysfunctional families rather than an illness.<sup>45</sup> The NSF opposed hospital closures, believing institutionalisation to be a realistic interim measure until community-based services for the mentally ill were adequately provided. Whilst some community care supporters argued that drug treatments could provide a real alternative to institutionalisation, the NSF, and indeed Pringle in 'A Case of Schizophrenia', contested that drug therapies did not relieve the burden of care placed on families.<sup>46</sup> Sociologist Nick Crossley has explained how this position led to tension between the NSF and MIND: 'In effect, the NSF [was] calling for a more robust use

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<sup>44</sup> Anne Rogers and David Pilgrim, *Mental Health Policy in Britain* (2nd edn, Basingstoke and New York, 2001), p. 239.

<sup>45</sup> The Mental Patients Union also disagreed with proponents of anti-psychiatry, but for different reasons to the NSF: Crossley, *Contesting*, p. 163.

<sup>46</sup> Crossley, *Contesting*, p. 141.

of psychiatric labels and interventions, quicker diagnoses and treatment with more drugs and less equivocation, whilst MIND [was] challenging labels and interventions.'<sup>47</sup> In doing so the NSF was prioritising the needs of relatives of those with schizophrenia, the main basis of its membership.

From the mid-1970s the NSF began to lobby Parliament to try and influence social policy decisions. Crossley has posited that the NSF, in many respects a paternalistic organisation, was progressive in the sense that it challenged the government position on mental health care legislation.<sup>48</sup> Dorothy Silberston became involved in drafting the NSF response to social policy documents, and from 1982 she became the Honorary Parliamentary Officer of the NSF, as well as being a member and later chair of the NSF Medico-legal Committee. Dorothy Silberston, whose daughter Catherine had been diagnosed with schizophrenia in 1961, set up a local group called the Relatives of Mentally Ill Patients in Cambridge in 1965. She became a founder member of the NSF, and was one of the initial respondents to Pringle's letter in *The Times*. Silberston had a vast range of relevant experience to bring to her roles in the NSF, having been awarded a social science diploma from the London School of Economics in 1946, working as a social worker, and serving as a Labour County Councillor in Cambridge from 1969 until 1973. In Autumn 1992 Silberston reflected:

I've learned an awful lot about procedures, all the different stages of a Bill, how to use written and oral questions, and Early Day Motions, how to persuade MPs and Peeps about the validity of NSF's views, which are borne out of first-hand

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<sup>47</sup> Ibid., p. 141.

<sup>48</sup> Ibid., pp. 141-42.

experience. We've got a long list now of over 100 MPs and 60 Peers who are sympathetic to NSF. Our voice is being heard more clearly now than ever.<sup>49</sup>

In 1973 Silberston provided evidence to Sir Keith Joseph, the Conservative Secretary of State for Social Services, detailing her experience as the mother of a girl hospitalised for schizophrenia treatment. Silberston anonymously explained: 'we shall never willingly have [our daughter, Catherine] to live at home with us, unless she is out, reliably, for part of most days. And as this cannot happen, in present circumstances, if she is discharged we shall cope because we are forced to and have no alternative.'<sup>50</sup> Silberston's account summarised the main campaigning positions of the NSF which were to feature in subsequent lobbying efforts: the need for the opinions of family members to be taken into account, and the burden that would be placed on families if patients were to be discharged from hospital. In 1974 the NSF reasserted its position that 'relatives of chronic schizophrenics living in the community who accept a caring responsibility for them are "primary care" agents and should be recognised as such in policy-making and administration.'<sup>51</sup>

In 1982 the NSF raised concerns about the Mental Health (Amendment) Bill which proposed limiting the rights of the 'nearest relative' and further limiting the agency of relatives over mental health care. On 13 January 1982 Pringle wrote to Conservative MP David Atkinson arguing that: 'one matter to which we attach importance is the definition of the "nearest relative" . . . the crucial question is not

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<sup>49</sup> Joanna Gamester, 'Dorothy Silberston M.B.E., 1921-2006', *Nuffield College Annual Report: Academic Report*. <[www.nuffield.ox.ac.uk/About/Documents](http://www.nuffield.ox.ac.uk/About/Documents)> (11 December 2014), pp. 7-9; WL, PP/DSI/C/4/4, *NSF Today* (Autumn 1992), pp. 6-7.

<sup>50</sup> WL, PP/DSI/B/2, Misc Policy Papers, *D. Silberston Provides Evidence for Sir Keith Jenkins* (December 1973), p. 11.

<sup>51</sup> PP/DSI/C/1/1, *Social Provision for Sufferers from Chronic Schizophrenia* (June 1974), p. 11.

one of consanguinity but of the caring relationship.<sup>52</sup> Silberston gave evidence to the Mental Health (Amendment) Bill committee headed by Kenneth Clarke, Conservative Minister for Health, in November 1982. She explained, in opposition to the position taken by MIND, that the NSF's concerns related to the proposal that the nearest relative would no longer be able to apply for a patient to be detained without the agreement of a social worker: 'Delay is one of the serious problems. It is very difficult to get these people on the spot. Further, there is often a difference of opinion between the doctor and the social worker. We do not want to be able to do nothing at all.'<sup>53</sup>

The NSF was concerned that if the rights of the nearest relative were undermined families would lose a degree of agency of the care of their relative with schizophrenia. In a pamphlet published in 1983, the NSF proposed that 'nearest relative' should be replaced with 'caring relative', 'concerned relative', and 'friend' to distinguish between different relationships with service-users. 'Caring relative' was defined by the NSF as 'the close relative or family member who would normally and willingly offer a home to the mentally sick relative on discharge from Hospital.' 'Concerned relative' was to 'mean the relative whom, in the temporary or permanent absence of a caring relative, the patient would usually turn to for advice.' 'Friend' was defined as 'someone who in the absence of a caring or concerned relative, currently accepts some responsibility for the welfare of the patient.'<sup>54</sup> In line with the 1959 Mental Health Act, the 1982 Mental Health (Amendment) Act defined the nearest relative as a blood relation, unless the

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<sup>52</sup> WL, PP/DSI/B/2, Misc Policy Papers, *Letter to Mr Atkinson MP from John Pringle* (13 January 1982), p. 2.

<sup>53</sup> WL, PP/DSI/C/4/2, *NSF News* (November 1982), pp. 2-3.

<sup>54</sup> WL, PP/DSI/C/1/9, *Good Relations: A Code of Practice for those Discharging Patients* (1983), p. 3.

individual was adopted. However, the 1982 Act was amended for when a blood relative could not be found but the patient had lived with a non-family member for a period of more than five years and this individual could then act as the nearest relative.<sup>55</sup>

The minutes of the NSF's Annual General Meeting (AGM) on 2 October 1982 are particularly illuminating of the NSF's position in relation to policy decisions, and particularly the proposed Mental Health Act. Concern was expressed about a proposal in the Mental Health (Amendment) Bill for patients hospitalised for 28 days under compulsory orders to appeal against their detention during the first 14 days. The NSF wanted 'to ensure that a person who becomes seriously disturbed can be given care and treatment as soon as possible.'<sup>56</sup> Silberston, who had campaigned extensively for the NSF's views to be considered in the drafting of the bill, explained that:

The NSF had been too late in taking action. This all party bill had support from the last labour government as well as the present government. In the main elements organisations like MIND had persuaded the government to include matters which we find very worrying. . . We think that this bill is unrealistic and impractical / it emerged clearly that the view of the opposition in the committee was anti-psychiatrist and that relatives were wicked in consigning patients to hospital.<sup>57</sup>

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<sup>55</sup> Mental Health Act: 7 & 8 Eliz. 2., Ch. 72 (London, 1959), pp. 34-35; Mental Health (Amendment) Act: Ch. 51 (London, 1982), pp. 10-11.

<sup>56</sup> WL, PP/DSI/A/3/1, Summary of 2<sup>nd</sup> October 1982 AGM (1982), pp. 2-3.

<sup>57</sup> Ibid., p. 8.



During the AGM the NSF resolved to fight the closure of two mental hospitals in the North East Thames regional health authority, Friern and Claybury, closures which were already endorsed by MIND. As 'most of the patients were schizophrenic with elderly relatives', the NSF was concerned about who would provide care with an absence of adequate community services.<sup>58</sup> Both mental hospitals were subsequently closed, but not until the 1990s. The decision was made to close Friern in 1989, with the official closure in April 1993, and Claybury was closed in 1997.

Some NSF members did not feel that the NSF was doing enough to campaign effectively for positive change to mental health care provision. Peter Sedgwick, author of *PsychoPolitics* (1982), resigned from the NSF's Council of Management during the AGM. Sedgwick explained the reasoning behind his decision:

The government got support from a network of relatives and sufferers providing in many cases a 24-hour nursing service, education professionals and dealing with the many economic problems of care-giving . . . [the government is] getting a very good bargain with us and knows it. We are told that the need for the Mental Hospital has been largely superseded by modern drugs, which is allegedly curing patients, so that long term hospitalisation is not needed. This is only partially true. Some patients do not respond well to drugs. The hidden factor keeping patients out of hospital is mainly that we are providing excellent unpaid nursing services. Proud as we may be at this, it must not be used as an excuse for denying professional

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<sup>58</sup> WL, PP/DSI/A/3/1, Summary of 2<sup>nd</sup> October 1982 AGM (1982), p. 7.

nursing services; nor should we develop a tendency for Groups to provide services that have not been provided by the statutory services.<sup>59</sup>

Following Sedgwick's resignation and John Pringle's death in 1983, NSF medical advisor John Wing restated the aims of the NSF. In addition to stressing that the ideal alternative to mental hospital admission was the establishment of campus, or Haven, communities, Wing stated that 'the NSF should be run by relatives'. Wing expressed that 'the Fellowship is close to realising many of its basic aims' and that 'it is now possible to talk openly about the good aspects of institutions and the bad aspects of the alternatives without necessarily being thought impossibly reactionary.'<sup>60</sup>

In 1985 the NSF began a 'Cart before the Horse Campaign' to fight mental hospital closures. The March 1985 edition of the *Psychiatric Bulletin of the Royal Society of Psychiatrists* restated the position of the NSF via two articles: one a letter from the NSF's four medical advisers, and the other a transcript of correspondence between the NSF and the Secretary of State for Health, Kenneth Clarke, about hospital closures.<sup>61</sup> The letter from medical advisers, Carstairs, Early, Rollin, and Wing, urged medical professionals to inform and include relatives. Rather than avoiding the use of labels, mental health professionals were urged to be open and

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<sup>59</sup> WL, PP/DSI/A/3/1, Summary of 2<sup>nd</sup> October 1982 AGM (1982), pp. 3-5.

<sup>60</sup> WL, PP/DSI/A/3/1, John Wing, *Where do we go from here?* (September 1984), pp. 1-4.

<sup>61</sup> 'Hospital Closures and Community Care: Correspondence between the National Schizophrenia Fellowship and the Minister of Health', *Psychiatric Bulletin*, 9 (March 1985), pp. 49-55; G.M. Carstairs, D.F. Early, H.R. Rollin, and J.K. Wing, 'Informing Relatives about Schizophrenia', *Psychiatric Bulletin*, 9 (March 1985), pp. 59-60.

honest about the diagnosis and prognosis of the patient's condition and to view relatives as "'primary care" givers'.<sup>62</sup>

The letter from the NSF's medical advisers was anti-anti-psychiatric in tone and in 1986, following the MIND annual conference of November 1985, the NSF explicitly restated its position towards MIND and the service-user movement.<sup>63</sup> The April 1986 edition of *NSF News* keenly stated that the NSF had a good relationship and degree of co-operation with local MIND organisations which provided local services for those with schizophrenia and their families. However, in the newsletter, the NSF also restated their view that families did not cause schizophrenia:

Current research suggests that schizophrenia has a physical basis, vulnerability to the illness seems to be often genetically transmitted. Although stress is recognised as a possible triggering factor, nothing suggests that the incidence of schizophrenia is related to the way society is organised; its incidence rate is similar in widely different kinds of societies.<sup>64</sup>

Additionally, the NSF stated its opposition to views espoused by the MIND head office. In particular, it criticised MND's support for hospital closures, for service-user rights to be extended, and for service-users to be able to run their own services if they wished. The NSF stated:

Schizophrenia is an illness which can seriously affect the level of functioning undermining perception and ability to make reasoned decisions, organise

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<sup>62</sup> Carstairs, Early, Rollin and Wing, 'Informing', pp. 59-60.

<sup>63</sup> Crossley, *Contesting*, p. 4.

<sup>64</sup> WL, PP/DSI/C/4/2, *NSF News* (April 1986), p. 2.

effectively, or present views coherently. NSF wishes sufferers, families and carers to be consulted about treatment, care and services as much as possible but feels from experience that it is impractical to expect sufferers to run their own services.<sup>65</sup>

The following year the NSF criticised MIND following the MIND annual conference of November 1986: 'while carers get a nodding mention in MIND's Charter, not a single workshop at the conference was devoted to carers' needs, and NSF people present felt that none of the platform speakers addressed that issue in a proper manner.'<sup>66</sup>

The continued difference of focus between NSF and MIND is illustrated by the NSF setting up National Voices in 1987, the same year that MIND set up MINDLink. MINDLink was a network of service-users and survivors. National Voices was also a service-user network. Richard Jameson, the first Chairman of Voices, described the benefits of the forum: 'We have firsthand experience of Schizophrenia having been through the mill ourselves and therefore we feel we have a lot to offer the sufferer. If he won't take advice from doctors and all kinds of well-wishers, he may well listen to us because we are on the same wavelength.'<sup>67</sup> However, Voices was based on the following ethos, which closely echoed the views of the NSF.

[National Voices] accepts the medical label of schizophrenia, describes users as 'sufferers', and accepts the likelihood that the condition is biologically caused.

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<sup>65</sup> WL, PP/DSI/C/4/2, *NSF News* (April 1986), p. 2.

<sup>66</sup> WL, PP/DSI/C/4/2, *NSF News* (April 1986), p. 2; WL, PP/DSI/C/4/3, *NSF News* (February 1987).

<sup>67</sup> WL, PP/DSI/C/4/3, *NSF News* (August 1987), p. 15.

However, these people also defend their right to be heard about the quality of service delivery from their own experience and perspective.<sup>68</sup>

The NSF was actively extending the support it gave to service-users, although in a way that differed in approach from MIND. A telling example of this difference is apparent in MIND's objections towards the use of the term 'sufferer', which was commonly deployed by the NSF.

In conclusion, by the mid-1980s the NSF had secured itself a position as a Parliamentary lobby group, affording the Fellowship the opportunity to contribute to debates prior to the enactment of the Mental Health Act in 1983. The NSF positioned itself against service-user organisations, particularly MIND, and was openly critical of those who were associated with anti-psychiatry. The NSF medical advisers, along with the NSF Parliamentary Officer, Dorothy Silberston, worked to foster support for the view that schizophrenia was a mental illness which required specific services to provide treatment for sufferers, but also to promote the well-being of affected families. The NSF's campaigns focused on fighting hospital closures before adequate community services were established, and bolstering the rights of relatives, both in terms of rejecting the burden of care, but also having their voices heard and respected by mental health care professionals. These campaigns raised the profile of the relatives of schizophrenia patients during the early 1980s when the term 'carer' was entering widespread usage. Largely as a response to the manner in which MIND adopted a rights-based approach, the NSF also began to adopt a discourse of rights in its campaigns. As service-users and

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<sup>68</sup> Rogers and Pilgrim, *Policy*, p. 117.

psychiatrists were vying for rights and power in the context of community care, the NSF actively sought to raise the profile and needs of relatives. In doing so the NSF reinforced the emergent category of the carer.

### **Equal Partners, c. 1987-1999**

Sociologist Anne Rogers and mental health academic David Pilgrim have suggested that after the mid-1980s the NSF 'shifted away from . . . opposing hospital run-down and closure . . . [to place] more of an emphasis upon a well-resourced range of services.'<sup>69</sup> Indeed, the NSF began to campaign for, and indeed to provide, a range of mental health services during the late 1980s and 1990s. The NSF worked alongside the Initiative to Reduce the Impact of Schizophrenia (IRIS) in the West Midlands and, in 1992, the NSF set up a National Advice Service. By 1993 the NSF had grown to have 6446 members, a total of 160 support groups and 200 projects.<sup>70</sup> Contrary to the assertion by Rogers and Pilgrim, however, the NSF continued to actively oppose hospital closures during the late 1980s and 1990s. Speaking at the Royal Society of Arts on 13 May 1987, NSF medical advisor John Wing 'argued that the pace of change, with timetables for hospital closures is now so great that it is difficult to control if things go wrong.'<sup>71</sup> In May 1988 *NSF News* outlined the details of hospital closures throughout the country and stated that the NSF campaign to halt the closures continued 'to gain support from among MPs and

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<sup>69</sup> Ibid., p. 214.

<sup>70</sup> WL, PP/DSI/F/1, *NSF: The first twenty-one years, 1972-1993* (September 1973), p. 6.

<sup>71</sup> WL, PP/DSI/C/4/3, *NSF News* (August 1987), p. 5.

Peers of all parties, and hundreds of people, many of them professionals'.<sup>72</sup>

Conservative MP Charles Irving, chairman of the All-Party Mental Health Committee (1979-92), presented an Early Day Motion opposing hospital closures in 1989.

Irving positively received the news 'that that the closure of mental illness hospitals is not a primary aim of Government policy; and [that he should] review urgently the current and planned pace of rundown of these hospitals'.<sup>73</sup> The Autumn 1993 edition of the NSF's newsletter, by then entitled *NSF Today*, outlined the NSF's ten-point-plan. Listed as number one was a freeze on closures of mental hospitals.<sup>74</sup> In 1991 the NSF wrote to William Waldegrave, the Conservative Secretary of State for Health, to promote the idea of using the sites of old mental hospitals to set up Haven Communities, an idea which had previously been suggested by John Wing in 1983.<sup>75</sup>

The eighth point of the NSF's ten-point-plan was 'care for the carers'.<sup>76</sup> In May 1988 the NSF commented on the green paper, *Community Care: The Next Decade and Beyond* (1988), commonly referred to as the Griffiths' Report: 'above all, the report is a milestone in the recognition of the importance of family carers and giving them support.'<sup>77</sup> The Griffiths' report, supported additional practical support for carers, but the NSF was concerned that this was not becoming a reality, despite assurances from Conservative Secretary of State for Health Virginia

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<sup>72</sup> WL, PP/DSI/C/4/3, *NSF News* (May 1988), p.1, pp. 4-5.

<sup>73</sup> WL, PP/DSI/C/4/3, *NSF News* (February 1989), p. 2.

<sup>74</sup> WL, PP/DSI/C/4/4, *NSF Today* (Autumn 1993), pp. 10-11.

<sup>75</sup> WL, PP/DSI/A/3/1, Wing, *Where do we go from here?*, pp. 1-4; WL, PP/DSI/C/4/4, *NSF Today* (February 1991), p. 15.

<sup>76</sup> WL, PP/DSI/C/4/4, *NSF Today* (Autumn 1993), pp. 10-11.

<sup>77</sup> WL, PP/DSI/C/4/3, *NSF News* (May 1988), p.1.

Bottomley.<sup>78</sup> Bottomley had previously worked as a researcher for the Child Poverty Action Group and had been Vice Chair of the National Council of Carers.<sup>79</sup> The NSF expressed in the October 1994 edition of *NSF Today* that the reduction of hospital beds and psychiatric nurses, which followed the National Health Service (NHS) and Community Care Act (1990), counteracted the promise of more practical support for carers outlined in the Griffiths' report. There was a subsequent vigil held outside Bottomley's office which the NSF considered to be a success.<sup>80</sup>

By recognising the need for greater service provision for both service-users and carers, the Griffiths' report did, however, have a more concrete influence on the relationship between the NSF and MIND.<sup>81</sup> Whilst the NSF continued its campaign to halt hospital closures, and continued to first-and-foremost promote the interests of carers, relations between the NSF and MIND did begin to thaw from 1987 onwards. In November 1987 *NSF News* enclosed a leaflet advertising MIND's magazine, *OPENMIND*, and vice versa.<sup>82</sup> As stated in August 1989:

While the Fellowship and MIND . . . do not agree on everything, we are determined to work more closely together where we can find issues that we do agree on. We have to apply as much pressure as we can to get better services for people with mental health problems, and it damages both organisations if we appear to be

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<sup>78</sup> 'On the front line of care: Doctors and social workers are among the critics of the way the new community-care system functions', *Guardian*, 12 May 1992, p. 3; 'Who cares?', *Guardian*, 12 May 1992, p. 1.

<sup>79</sup> 'Virginia Bottomley', *Guardian*, 5 January 1993, p. 3.

<sup>80</sup> WL, PP/DSI/C/4/4, *NSF Today* (October 1994), p. 2; WL, PP/DSI/C/4/4, *NSF Today* (January 1995), pp. 4-5.

<sup>81</sup> For more on the Griffiths Report see Chapter Four of this thesis.

<sup>82</sup> WL, PP/DSI/C/4/3, *NSF News: NSF Extra* (November 1987).



fighting with each other all the time. We plan to hold regular meetings involving senior staff from both organisations.<sup>83</sup>

Despite this greater collaboration between NSF and MIND, tensions continued to exist, particularly in relation to the differing interests of service-users and carers. In an August 1991 interview by NSF Research and Communications Officer, Jerry Westall, with MIND's Ron Lacey, Lacey asserted: 'you have to recognise that the interests of the family and the interests of the individual are not always in harmony.' Westall had previously served as the NSF's Policy Officer. Lacey had previously been a psychotherapist and a social worker before working for MIND, where he had been Assistant Director of MIND working closely with Larry Gostin and campaigning for the 1983 Mental Health Act.<sup>84</sup> In another interview by Westall, MIND's legal director William Bingley reiterated Lacey's point: 'Patients and carers sometimes have very different views about what should happen to them.' Westall responded that 'both NSF and MIND are trying to represent both points of view. NSF with its support of Voices and MIND now say they are interested in the rights of carers as well as users.'<sup>85</sup>

Whilst the NSF increasingly campaigned on behalf of users as well as carers, its primary focus continued to be to campaign for better services and a greater recognition of the role and needs of relatives, now known as carers. Indeed, the NSF began to collaborate with SANE (Schizophrenia A National Emergency!), a controversial organisation supporting relatives and communities, that MIND

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<sup>83</sup> WL, PP/DSI/C/4/3, *NSF News* (August 1989), p. 2.

<sup>84</sup> WL, PP/DSI/C/4/3, *NSF News* (August 1991), pp. 4-5.

<sup>85</sup> WL, PP/DSI/C/4/3, *NSF News* (August 1990), pp. 4-5.

vehemently opposed.<sup>86</sup> SANE was founded in 1986 by journalist Marjorie Wallace following the publication of a series of her articles in *The Times* entitled 'The Forgotten Illness'. SANE strongly opposed care in the community and set out to spread awareness that without adequate services people diagnosed with schizophrenia could end up homeless or in prison. The organisation also sought to combat stigma and provide support for people with mental health problems, along with their families and carers. MIND and other service-user groups opposed SANE because they felt that SANE further stigmatised the mentally ill as violent and out of control.<sup>87</sup>

In the late 1980s and throughout the 1990s the NSF continued to encourage its members to write to their MPs, to share their personal experiences with one another, and to commission surveys of carers and sufferers.<sup>88</sup> In 1988 psychologist Jacqueline Atkinson surveyed NSF members (449 relatives and 356 sufferers). Atkinson's report showed that 'families have multiple burdens' and she noted that 'when the analysis is completed I will be using this survey in the fight for better services.'<sup>89</sup>

In 1989 the NSF stated a new campaign priority: 'to widen the group of carers to which the NSF appeals, especially making our services and support appropriate and available to those in the Inner Cities and to the different ethnic,

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<sup>86</sup> WL, PP/DSI/C/4/3, *NSF News* (August 1987), p. 3; WL, PP/DSI/C/4/3, *NSF News* (November 1988), p. 1.

<sup>87</sup> For an account of SANE's adversarial relationship with anti-psychiatry and MIND see: Crossley, *Contesting Psychiatry*, pp. 191-99.

<sup>88</sup> Letters to MPs: WL, PP/DSI/C/4/3, *NSF News* (February 1987), p. 5. Personal accounts: WL, PP/DSI/C/4/3, *NSF News* (May 1989), p. 11; WL, PP/DSI/C/4/4, *NSF Today* (Autumn 1992), pp. 14-15. Surveys: WL, PP/DSI/C/4/3, *NSF News* (August 1988), p. 7; WL, PP/DSI/C/4/4, *NSF Today* (Summer 1993), p. 8; WL, PP/DSI/C/4/5, *Your Voice* (Summer 1999), p. 5.

<sup>89</sup> WL, PP/DSI/C/4/3, *NSF News* (August 1988), p. 7.

religious and cultural minorities.<sup>90</sup> From its inception, the main focus of the NSF had been parents and spouses. In January 1990, however, the NSF formally acknowledged another sub-category of carers, siblings, with a group dedicated to siblings being set up.<sup>91</sup> Whilst links between ethnicity and schizophrenia were the subject of much research by social researchers and medical professionals, the NSF rarely discussed ethnicity before the early 1990s. This started to change in 1991 when *NSF News* featured an interview with Dr Aggreby discussing the relationship between race and schizophrenia.<sup>92</sup> Subsequent surveys and questionnaires commissioned by the NSF set out to find out more about the different types of carers including elderly carers and young carers. For instance, the Winter 1997/1998 edition of *NSF Today* asked elderly carers to contact the NSF with their particular needs as carers.<sup>93</sup> Also, the Winter 1999/2000 edition of *Your Voice* explained that the NSF wanted more research to be conducted into Young Carers: 'little is known about the particular experiences and needs of children caring for a co-resident relative with severe and enduring mental health problems.'<sup>94</sup>

In 1995 the NSF published a summary of its major survey of the needs of carers' of severe mental illness, commissioned by the NHS Mental Health Task Force and designed to provide a representative view of carers which could then be extrapolated.<sup>95</sup> *The Silent Partners* marked a departure from the NSF's previous primary focus on schizophrenia, a move which was cemented in 2002 when the

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<sup>90</sup> WL, PP/DSI/C/4/3, *NSF News* (August 1989), p. 2.

<sup>91</sup> WL, PP/DSI/C/4/3, *NSF News* (February 1991), p. 15.

<sup>92</sup> Ibid., pp. 4-5.

<sup>93</sup> WL, PP/DSI/C/4/4, *NSF Today* (Winter 1997/98), p.5.

<sup>94</sup> WL, PP/DSI/C/4/5, *Your Voice* (Winter 1999/2000), pp. 12-13.

<sup>95</sup> For a detailed analysis of the place of the survey in the emergence of the category of the carer see Chapter Two.

organisation changed its operating name to *Rethink: Mental Illness*. In 1993 the Department of Health's Mental Health Task Force asked the NSF to conduct a survey of 'who carers were and what they wanted'.<sup>96</sup> 1,923 carers took part, although only 345 answered the second, more detailed, questionnaire. To address the unrepresentative nature of the NSF's membership the methodology was designed to include more carers from minority groups in the sample.<sup>97</sup>

*The Silent Partners* aimed 'to continue the focus on carers' needs and apply pressure to policy makers, service providers and purchasers to recognise carers' concerns, via its three objectives: to raise the profile of informal carers; to discuss the needs and experiences of informal carers; and for informal carers to discuss their own needs.<sup>98</sup> The report also clearly indicated the NSF's view of carers:

- 1) Every carer has individual caring responsibilities and individual needs. Carers cannot be classified as one group with a shared set of needs.
- 2) Carers are experts in severe mental illness.
- 3) Carers do not always want to care.
- 4) Carers have a low ceiling in terms of requests for services. They are not a group that make unrealistic demands.<sup>99</sup>

The report explained that the role of the carer ranged 'from speaking to someone on the telephone once a week to 24-hour support. Over time, carers are likely to

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<sup>96</sup> Hogman and Pearson, *Silent Partners*, p. 3.

<sup>97</sup> Ibid., p. 8.

<sup>98</sup> Ibid., p. 3, p. 55.

<sup>99</sup> Ibid., p. 4.

provide care at both these extremes.<sup>100</sup> A lack of services to support carers, was also indicated, both on a day-to-day basis, and at times of crisis: 'services are naturally focused on the patients, whilst the carers' needs are neglected'.<sup>101</sup> NSF researchers Gary Hogman and Guy Pearson, who published the report's findings as *The Silent Partners*, found 'a creeping "institutionalisation" of the carer', with carers often unable, or feeling unable, to choose whether to provide care. The report concluded that community care should be based on a 'needs-led approach' with better provision of, and access to, services, particularly in times of crisis. The health and social needs of carers were often neglected, as well as their work prospects. Carers were said to need more information, in terms of diagnosis and treatment, but Hogman and Pearson noted that 'information sharing' should be a priority because 'carers' knowledge of the sufferer is greater than anyone else's'.<sup>102</sup> The report's main conclusion was that '[Carers] want to be treated as an equal partner in the care team and to immediate help and advice when needed'.<sup>103</sup> The findings presented in *The Silent Partners* reiterated much of the NSF's rhetoric from the 1970s and 1980s by stressing, on the one hand, the burden of caring, and, on the other hand, the need for greater recognition of the role and experience of caring relatives, or as they were now known, carers.<sup>104</sup>

In 1997 the NSF published a booklet in which it outlined its vision for the relationship between service-users, carers, and professionals. The booklet resulted from two NSF conferences, held in November 1991 and March 1992, attended by

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<sup>100</sup> Ibid., p.12.

<sup>101</sup> Ibid., p. 6.

<sup>102</sup> Ibid., pp. 46-51.

<sup>103</sup> Hogman and Pearson, *Silent Partners*, p. 49. See also, PP/DSI/C/4/4, *NSF Today: NSF Extra* (April 1995), p. 3.

<sup>104</sup> Hogman and Pearson, *Silent Partners*, p. 3.

professionals, service-users, and carers. The booklet defined a carer as 'someone, usually a relative or friend, who provides a significant level of support to a service-user, though not necessarily living with them.' The booklet included guidelines to promote greater involvement, defined as 'taking an active part through being listened to and contributing to processes, of service-users and carers in mental health care.'<sup>105</sup> The NSF perceived services users, carers, and professionals as 'care partners' which fitted with the NSF's view that relatives should be recognised as primary care agents:

Everyone involved in the delivery of care, including service-users and carers, should be treated as equal partners. Occasionally, some professionals may initially feel threatened by the involvement of service-users and carers . . . It is essential to remember that every care partner brings something different, but equally valuable, to the relationship and that successful delivery of care depends on effective collaboration between the care partners.<sup>106</sup>

The NSF's vision went beyond rhetoric when, in 1994, the Sainsbury Centre for Mental Health Development approached the NSF to collaborate in setting up a Carers Support Project, which became known as the Education and Support Programme for Carers (CESP).<sup>107</sup> The eleven-week programme, piloted in 1997, was designed 'to provide carers of people with serious mental health problems with the

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<sup>105</sup> National Schizophrenia Fellowship, *How to Involve Users and Carers in Planning, Running, and Monitoring Care Services and Curriculum Development* (Kingston-Upon-Thames, 1997), p. 2.

<sup>106</sup> NSF, *Users and Carers*, p. 10.

<sup>107</sup> Lyn Shore, *Learning to Cope Together: Implementation and Evaluation of the NSF/Sainsbury Centre for Mental Health Carers' Education and Support Project CESP* (Kingston-Upon-Thames, 1998), p. 4; WL, PP/DSI/C/4/4, *NSF Today* (Spring 1996), p. 6.

knowledge, skills and confidence to deal more effectively with their role. Outcomes will improve the health of the carers themselves, and that of the family member for whom they are caring.<sup>108</sup> CESP was a response to research finding that 'as many as 50 per cent of people who now leave psychiatric care are discharged into the care of their families'. The programme was also a response to growing recognition by social policy makers and professionals that carers were major providers of community care, and that they needed greater recognition and better service provision.<sup>109</sup> By September 1998, over seventy carers, with almost equal numbers of men and women, comprising of parents, partners, and siblings, had taken part in CESP groups.<sup>110</sup> Edna, a carer, who attended the Lewes District CESP, run by carer Lyn Shore, from November 1997 until February 1998, reflected on her experience:

we felt like a caring, responsible family, instead of the enemy who has caused this terrible illness to happen. . . Surely the way forward with an illness so devastating as schizophrenia, where there is still a lot to discover, is for co-operation and support between everyone concerned.<sup>111</sup>

The 1999 national strategy, *Caring about Carers*, acknowledged the important role that carers played in community care and that the well-being of these carers needed to be a priority in order to maintain this key resource.<sup>112</sup> *Caring about Carers* reflected the views of the NSF, which in conjunction with research by

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<sup>108</sup> Department of Health, *National Service Framework for Mental Health: Modern Standards and Service Models* (London, 1999), p. 73.

<sup>109</sup> Shore, *Learning*, p. 5.

<sup>110</sup> *Ibid.*, p. 16.

<sup>111</sup> *Ibid.*, pp. 2-3.

<sup>112</sup> *Caring about Carers* is examined in Chapter One of this thesis.

its medical advisers, promoted the well-being of relatives as a priority in the care of those with schizophrenia sufferers and their families. In September 1999 another of the NSF's views, the notion that carers should be recognised as having a central role within mental health care, was included in the National Services Framework for Mental Health.<sup>113</sup> Building upon the white paper *Caring for People* (1989) and the Carers (Recognition and Services) Act (1995) the framework included 'Caring for Carers' as one of their seven standards, or objectives.<sup>114</sup> The other standards were: mental health promotion; primary care and access to services; effective services for people with severe mental illness; preventing suicide. The Framework acknowledged the problems faced by carers and proposed ways to assist carers and to promote their well-being.<sup>115</sup> In addition, and in line with the position taken by the NSF, carers were listed as one of the stakeholders in mental health care.<sup>116</sup> In 2001, Rogers and Pilgrim stated: 'the needs of relatives should have separate consideration within mental health policy and provision. It may not be assumed that their needs and difficulties are the same as those of the carers of other groups of people, nor may it be assumed that their needs are the same as those being cared for.'<sup>117</sup> The Framework addressed this issue, but, as also argued by Rogers and Pilgrim, the published Framework was a compromise of disparate interest groups, including the NSF and MIND. This need to compromise slowed down the publication of the Framework, but a consensus was reached, which demonstrates

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<sup>113</sup> DH, *Framework*.

<sup>114</sup> See Chapter One for more information on *Caring about Carers* (1989) and Carers (Recognition and Services) Act (1995).

<sup>115</sup> DH, *Framework*, pp. 69-75.

<sup>116</sup> *Ibid.*, p. 89.

<sup>117</sup> Rogers and Pilgrim, *Policy*, pp. 121-22.



how far the relationship between service-user and carer groups had improved since the 1970s.<sup>118</sup>

By the publication of *Caring about Carers*, the NSF's objective that the relatives of those with schizophrenia should be recognised by the medical profession and social policy makers as primary care agents who needed their own services had been fulfilled. Carers and service-users were acknowledged in their own right and were conceptualised as having their own needs and opinions. This paved the way for greater cooperation between the NSF and service-user organisations, including MIND, with which the NSF had historically shared an adversarial relationship. Both organisations, along with other mental health organisations, felt, however, that more needed to be done to improve the lives of those service-users and carers and thus they continued to campaign for change. In November 1999 the government published a green paper, *Review of the Mental Health Act 1983*, which proposed extending compulsory powers held by medical professionals beyond hospitals via Community Treatment Orders.<sup>119</sup> Following the publication of the *Review* a number of organisations, including MIND, the NSF, the Manic Depressive Fellowship, and the Mental After-Care Association presented a petition with over 20,000 signatures to the Department of Health from service-users, carers, and professionals, in favour of 'a policy of care for the majority rather than control for the few.'<sup>120</sup> Later in 1999 around fifty organisations, including the Royal College of Psychiatrists, professionals, service-user groups, including MIND, and carer groups, including the NSF, joined forces to form the Mental Health

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<sup>118</sup> Ibid., p. 214.

<sup>119</sup> Department of Health, *Review of the Mental Health Act 1983: Report of the Expert Committee* (London, 1999).

<sup>120</sup> Rogers and Pilgrim, *Policy*, p. 218.

Alliance. The Mental Health Alliance opposed proposed changes to the Mental Health Act (1983) on the grounds that they did not support unnecessary compulsory treatment of the mentally ill. SANE was not initially a member of the Alliance, which was critical of the activities of SANE which it felt supported moves towards compulsory treatment.

In conclusion, during the late 1980s and throughout the 1990s the NSF continued to contribute to, and negotiate, the growing recognition of the carer for severe mental illness. The NSF supported its aims by conducting surveys of carers needs, including *The Silent Partners*, and creating services for carers, such as CESP. The NSF employed these methods to support their campaign for greater recognition of the role and needs of carers, whilst supporting carers' right to choose whether they provided care or not. Whilst the NSF continued to campaign to halt the closure of mental hospitals and strove to 'care for the carers', the previously tense relationship between the NSF and MIND began to thaw following the Griffiths' Report. In 1999 the NSF and MIND joined forces with other mental health organisations to form the Mental Health Alliance to campaign against proposed revision to the 1983 Mental Health Act. The NSF and MIND maintained their respective key foci of carers and service-users, but they also began to acknowledge the need for better services across the board and both did more to support the interests of both groups. The NSF campaigned for carers to be viewed as partners in mental health care provision, alongside service-users and professions. The 1999 National Service Framework for Mental Health acknowledged service-users, professionals, and carers as the key stakeholders in mental health care service provision. The NSF felt that, in reality, service provision for both carers and service-

users, along with professional understandings of both parties, could still be much improved and its campaign continued.

## **Conclusions**

This chapter has examined the ways in which the case study of the NSF during the 1970s, 1980s, and 1990s can inform our understanding of the history of the emergence of the category of the carer for severe mental illness. The NSF, the largest group of carers for people with severe mental illnesses in England, emerged in a similar way to other carer groups, including the National Association for the Parents of Backwards Children, following a letter to a national newspaper. The NSF, and the MIND campaign, also emerged in the context of moves towards community care. The NSF represented a group of relatives, and professionals, concerned that hasty hospital closures would place the burden of care for schizophrenia on the shoulders of relatives, and in particular parents. Schizophrenia was a widely debated and high-profile illness during the 1960s and 1970s due its unknown aetiology and concerns about hospitalised schizophrenics returning to the community. The NSF opposed the individuals associated with the so-called anti-psychiatry movement for blaming the family for the onset and relapse of schizophrenia. NSF members were encouraged to join mutual support groups and share their experiences, which helped these individuals to garner a collective identity. The NSF utilised accounts from its members, along with surveys of

members and other carers, to lobby Parliament and counter the popular view that schizophrenia was caused by relatives.

Throughout the 1970s until the mid-1980s the NSF had a tense relationship with service-user group, MIND. At this time, carers and service-users, and by extension the NSF and MIND, had conflicting interests, in terms of psychiatric understandings of mental illness, decisions over treatment, and how quickly mental hospitals should be closed. Although the NSF was not able to influence the outcome of the Mental Health Act of 1983, it was more successful in subsequent attempts to lobby Parliament.

The NSF wanted the government to provide services for carers, and service-users, but in the late 1980s the NSF began to provide services, including CESP, themselves. From this time onwards the tense relationship between the NSF and MIND began to thaw as the separate needs and rights of carers and service-users began to be acknowledged in social policy documents. The NSF had long campaigned for carers to be recognised as experts over their relative's care and for the well-being of these carers to be supported by targeted services. The NSF also wanted carers to have the right to choose whether to care for their relative, or not. By the late 1990s this aim had been fulfilled in terms of social policy rhetoric, although the NSF remained critical of the reality of the situation. The National Service Framework for Mental Health, published by the Department of Health in 1999, acknowledged carers, patients and service-users, and mental health professionals as stakeholders in mental health care provision.<sup>121</sup> In summary, the activities of the NSF from the 1970s onwards had raised the profile of the relatives

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<sup>121</sup> DH, *Framework*, p. 89.

of those with schizophrenia, and this ultimately contributed to a broader acknowledgement of the category of the carer. However, as this category emerged, the NSF negotiated the meanings attached to it and fought for relatives to reject their designation as 'carers' if they wanted to, but without acquiescing their rights.

# 6

## Post-war History of Mental Illness and Learning

### Disability: The Family Carer as Case Study

Historians have tended to separate the histories of mental illness and learning disability into two distinct fields of historical study. However, the report of the Royal Commission on the Law Relating to Mental Illness and Mental Deficiency published in 1957 explained that although the report distinguished between mental illness and mental deficiency, ‘there is no clear-cut medical distinction between the two: they are legal and administrative, rather than clinical, terms.’<sup>1</sup> Throughout the post-war period the boundaries between the categories of mental illness and mental deficiency (which later became ‘mental handicap’ and later still ‘learning disability’) were in fact ambiguous and often in flux. Distinctions and connotations that were made between the categories were made to serve particular purposes, be they diagnostic, as with the Diagnostic and Statistical Manual, or political, as with the 1959 Mental Health Act. To examine the history of mental illness and learning disability within the

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<sup>1</sup> *Report of the Royal Commission on the Law Relating to Mental Illness and Mental Deficiency, 1954-1957* (London, 1957), p. 5.

same study is to better understand the motivations and philosophies behind these distinctions and conflations made by actors in the past including non-governmental organisations, policy makers, professionals, and social researchers.

In this chapter, then, I argue that this well-established delineation has served to over-simplify the histories of both mental illness and learning disability in the post-war years. I use the history of the family carer as a case study to demonstrate the value of examining the often imprecise and permeable boundaries of the two categories. By studying the history of the carer in relation to both mental illness and learning disability, I argue, we can gain new insight and perspective on the histories of the family, community care, carers, mental illness, and learning disability. Firstly, I outline current historiographical trends. Secondly, I explore important distinctions that emerge between mental illness and learning disability when the two categories are studied in tandem. Thirdly, I examine the benefits of studying the emergence of the family carer in relation to both mental illness and learning disability. Rather than attempting to challenge the ambiguous boundary between the two fields, however, I suggest that it is the very study of the two in conjunction that serves to highlight these distinctive characteristics and adds new depth to the historical study of topics including the family carer.

## Mental Illness and Mental Handicap: Towards a New Historiography

Until recently the history of mental handicap, or learning disability, in post-war Britain has been studied separately from the history of mental illness. The boundaries between the two categories, however, were often blurred. To better understand the history of post-war mental health care it is necessary to consider both mental illness and mental handicap, and indeed the relationship between the two. Research into the care of people with learning disabilities outside of institutions did not begin until the 1990s, whilst the history of community care for those with mental illness was being written from the 1970s onwards.<sup>2</sup> Incorporating learning disability into the history of mental health care provides scholars with an opportunity to research an under-researched topic. Indeed, historian Mathew Thomson has stated that 'the subject of mental deficiency has . . . been neglected in the history of psychiatry', which Thomson argues results from a 'bias towards the history curing rather than caring, and a bias towards the history of psychiatrists and asylums rather than the care provided in the community by voluntary organisations, social workers, and families.'<sup>3</sup> As discussed in the introduction to this thesis, whilst historians of mental health care in the early modern and nineteenth-century have begun to challenge the established approach, it is only recently that twentieth-century

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<sup>2</sup> Jan Walmsley, Dorothy Atkinson, and Sheena Rolph, 'Community Care and Mental Deficiency 1913-1945', in Peter Bartlett and David Wright (eds), *Outside the Walls of the Asylum: The History of Community Care, 1750-2000* (London and New Brunswick, 1999), p. 186-87. Sociologist Kathleen Jones wrote early histories of the community care of the mentally ill. See: Kathleen Jones, *A History of Mental Health Services* (London, 1972); Kathleen Jones, *Mental Health and Social Policy, 1845-1959* (London, 1960).

<sup>3</sup> Mathew Thomson, *The Problem of Mental Deficiency: Eugenics, Democracy, and Social Policy in Britain, c. 1870-1959* (Oxford, 1998), p. 2.



historians have begun to do the same. Historians of inter-war Britain and England, including Mathew Thomson, Anne Digby, and David Wright, have examined community care in the mental health field.<sup>4</sup> However, the post-war period has attracted little attention. In terms of post-war mental health care and community care, mental illness and mental handicap had a complex interplay. This relationship demands scholarship in its own right.<sup>5</sup>

There has been some progress in integrating the history of learning disability into the history of mental healthcare, especially in relation to community, and familial, care.<sup>6</sup> However, little of this scholarship is focussed on the post-war period and the complex relationship between mental illness and learning disability is rarely addressed. Historians Peregrine Horden and Richard Smith's book *The Locus of Care* considers both mental illness and learning disability in its consideration of the history of mental health care and community care, but it does not explicitly unpick or problematise the complex relationship between the two categories. Instead the topics are delimited within distinct chapters written by different authors.<sup>7</sup>

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<sup>4</sup> Thomson, *Mental Deficiency*, p. 2; Jan Walmsley, Dorothy Atkinson, and Sheena Rolph conducted research based on Thomson's approach but did not venture into the post-war years: Jan Walmsley, Dorothy Atkinson, and Sheena Rolph, 'Community Care and Mental Deficiency 1913-1945', in Peter Bartlett and David Wright (eds), *Outside the Walls of the Asylum: The History of Community Care, 1750-2000* (London and New Brunswick, 1999), pp. 181-203. David Wright and Anne Digby also began to redress the marginality of people with learning disability in historical study through their edited collection, but the chapters within their volume also only went up to the inter-war years: David Wright and Anne Digby (eds), *From Mental Deficiency to Learning Disability: Historical Perspectives on People with Learning Disabilities* (London, 1996).

<sup>5</sup> For an overview of understudied aspects of the history of psychiatry, including mental handicap, see Roy Porter, 'History of Psychiatry in Britain', *Journal of the History of Psychiatry*, 2 (1991), pp. 271-79.

<sup>6</sup> S. Rolph, D. Atkinson, M. Nind, and J. Welshman (eds), *Witnesses to Change: Families, Learning Difficulties and History* (Kidderminster, 2005); Jan Walmsley and John Welshman, *Community Care in Perspective: Care, Control and Citizenship* (London, 2006).

<sup>7</sup> Peregrine Horden and Richard Smith (eds), *The Locus of Care: Families, Communities, Institutions and the Provision of Welfare since Antiquity* (London and New York, 1998).

Other edited volumes have taken a similar approach by siphoning mental illness and learning disability into different chapters. In *Mental Illness and Learning Disability Since 1850*, historians Pamela Dale and Joseph Melling employ 'mental disorder' as an umbrella term referring to both mental illness and learning disability but they do not explicitly unpick what they mean by this term.<sup>8</sup> Using the term 'mental disorder' as shorthand for mental illness and learning disability, however, belies the complexity of the relationship between the two categories. Yet, in the final chapter of the volume, historian of social policy, John Welshman begins to confront the tensions and continuities between the histories of mental illness and learning disability. In the conclusion to his study of hostel provision, Welshman states that 'exploring similarities and contrasts between hostels for the mentally ill and for people with learning difficulties is one important area for further research.'<sup>9</sup> Peter Bartlett and David Wright's 1999 edited volume, *Outside the Walls of the Asylum: The History of Care in the Community, 1750-2000*, features chapters on care in the community of mental illness and mental deficiency.<sup>10</sup> Again, whilst all of the other contributors consider either mental illness or mental deficiency, Welshman's chapter examined community care policies and services for the mentally ill and handicapped between 1948 and 1974.<sup>11</sup> As a historian of social

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<sup>8</sup> Pamela Dale and Joseph Melling, *Mental Illness and Learning Disability Since 1850: Finding a Place for Mental Disorder in the United Kingdom* (Abingdon, 2006).

<sup>9</sup> John Welshman, 'Inside the Walls of the Hostel, 1940-74', in Pamela Dale and Joseph Melling (eds), *Mental Illness and Learning Disability Since 1850: Finding a Place for Mental Disorder in the United Kingdom* (Abingdon, 2006), p. 219.

<sup>10</sup> Peter Bartlett and David Wright (eds), *Outside the Walls of the Asylum: The History of Community Care, 1750-2000* (London and New Brunswick, 1999).

<sup>11</sup> John Welshman, 'Rhetoric and Reality: Community Care in England and Wales, 1948-74', in Peter Bartlett and David Wright (eds), *Outside the Walls of the Asylum: The History of Community Care, 1750-2000* (London and New Brunswick, 1999), pp. 204-226. Welshman also implied that if the remit of this book had been different he could also have included domiciliary care of the elderly in his study: see p. 206.

policy rather than psychiatry, Welshman is well placed to adopt this innovative approach. As with Thomson's study of politics and mental deficiency, Welshman was concerned with the political and social policy contexts of mental health care. In these contexts the ill-defined boundary between mental illness and mental deficiency needed to be addressed by contemporaries to enable workable legislation to be implemented, to cater for the, often artificially, distinct groups of the mentally ill and the mentally deficient.

### **The Place of Mental Handicap in Post-War Mental Health Care**

Historian David Wright has examined the terminology of mental disability in Victorian England. Whilst a distinction was made between the terms 'lunacy' and 'idiocy', 'insane' was taken in Victorian legislation to mean "'idiots, lunatics and persons of unsound mind.'" Wright explained that 'in the context of Victorian England insanity was a legal and medical term encompassing the whole range of individuals who were not capable of conducting their affairs.' Wright also explained the distinction between 'lunacy' and 'idiocy': 'To use a common, if unkind, distinction made by the Victorians: "lunatics" were individuals who had a mind and lost it; "idiots" were individuals who never had a mind at all.'<sup>12</sup> This association of mental illness and mental handicap continued into the twentieth century and the post-war years. The report of the

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<sup>12</sup> David Wright, *Mental Disability in Victorian England: The Earlswood Asylum, 1847-1901* (Oxford, 2001), pp. 9-10.

Feversham Committee on voluntary mental health associations (1939) recommended that the Central Association for Mental Welfare (CAMW), the National Council for Mental Hygiene (NCMH), and the Child Guidance Council merge together. The CAMW and NCMH were concerned with mental handicap and mental illness, respectively. The CAMW been in support of community care since the 1920s and had begun to move towards an interest in mental health inter-war era.<sup>13</sup> From the outset the newly formed National Association for Mental Health (NAMH) considered both mental handicap and mental illness within its remit. Given the interests of the organisations which merged to form the NAMH, the new organisation lent towards mental health and mental hygiene in its focus rather than mental illness and mental deficiency.<sup>14</sup>

In the early post-war decades mental illness and mental deficiency both came under the remit of the Ministry of Health, which in 1968 became the Department of Health and Social Security. The legislative documents which dealt with mental health care often considered both groups, rather than taking it for granted that the groupings were discrete. This tended to problematise the distinction between the two. The report of the 1954-57 Royal Commission on the Law Relating to Mental Illness and Mental Deficiency attempted to define and distinguish between the two terms:

The term 'mentally defective' is used of patients whose minds have never fully developed or seem unlikely to do so. The term 'mentally ill' is applied to

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<sup>13</sup> Thomson, *Mental Deficiency*, pp. 153-56, pp. 175-77.

<sup>14</sup> Jonathan Toms, *Mental Hygiene and Psychiatry in Modern Britain* (Basingstoke: Palgrave, 2013), p. 30.

patients whose minds have previously functioned normally but have become disordered, usually in adult life. A person who is mentally defective may also develop a mental illness. Each term covers a wide range of types and degrees of disorder and there is no-clear cut medical distinction between the two: they are legal and administrative, rather than clinical terms.<sup>15</sup>

Finding these distinctions to be unhelpful, the report recommended that three new categories be employed instead: mentally ill patients; psychopathic patients, or patients with a psychopathic personality; and patients of severely subnormal personality. The report stated the reasons why the distinctions could be unhelpful:

The grouping of all types of defectives together, legally and administratively, has led to the supposition that they must be a more homogenous group of patients than they really are. This has led to resentment and misunderstanding on the part of the relatives of feeble-minded patients, and to a tendency in many quarters to assert that the higher-grade feeble-minded are not mentally defective. The care of feeble-minded patients has also been rigidly separated from the care of the mentally ill and from the forms of treatment which are now being developed for other psychopathic patients. We also consider that there are unnecessary difference between the procedures applied to mentally defective patients.<sup>16</sup>

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<sup>15</sup> Royal Commission (May 1957), p. 5. See also, C.H. Rolph, *Mental Disorder: A Brief Examination of the Report of the Royal Commission on the Law Relating to Mental Illness and Mental Deficiency, 1954-1957* (London, 1958), p. 5.

<sup>16</sup> Royal Commission (May 1957), p. 7.

In response, the 1959 Mental Health Act broadly defined "'mental disorder" [as] mental illness, arrested or incomplete development of mind, psychopathic disorder, and any other disorder or disability of mind'.<sup>17</sup>

During the post-war years, long-stay institutions for the mentally ill and the mentally handicapped began to close in favour of community care and acute institutional provision. Problematising the shared history of community care for mental illness and mental handicap in post-war England and Wales, Welshman has stated: 'changes in provision for the mentally ill have always occurred at a slower rate than for the mentally defective, perhaps because there has been greater fear of the former and more sympathy for the latter.' Indeed, the *Better Services for the Mentally Handicapped* (1971) white paper was published four years before *Better Services for the Mentally Ill*.<sup>18</sup> The move towards community care occurred earlier for mental deficiency than it did mental illness.<sup>19</sup> This contrast presents an opportunity for historians to ask new questions about, and gain new insight into, the history of post-war community care.

By the 1970s the term mental handicap was used in place of mental deficiency. Despite mentally handicapped children being transferred to the remit of the Department of Education and Science following the 1970 Education (Handicapped Children) Act, mental handicap continued to be considered within mental health legislation. One reason for this may have been that conditions such

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<sup>17</sup> Mental Health Act: 7 & 8 Eliz. 2., Ch. 72 (London, 1959), p. 2.

<sup>18</sup> Welshman, 'Rhetoric', pp. 206-07.

<sup>19</sup> Thomson, *Mental Deficiency*, pp. 194-95; Mathew Thomson, 'Sterilization, Segregation and Community Care: Ideology and Solutions to the Problem of Mental Deficiency in Inter-War London', *History of Psychiatry*, 3 (1992), p. 490. See also: Jan Walmsley, Dorothy Atkinson, and Sheena Rolph, 'Community Care and Mental Deficiency 1913-1945', in Peter Bartlett and David Wright (eds), *Outside the Walls of the Asylum: The History of Community Care, 1750-2000* (London and New Brunswick, 1999), pp. 181-203.

as autism were difficult to categorise. On 28 February 1985, a Social Services Committee stated: 'One particular group of people distinguished by the nature of their disability are autistic people, who suffer from a severe lifelong disability classified somewhere along the boundary of mental handicap and mental illness.'<sup>20</sup> Further, as historian Bonnie Evans has argued, as a result of closures of long stay institutions for mental defectives, more and more children and young people were diagnosed with autism from the 1960s onwards.<sup>21</sup> An increase in the number of children and young people diagnosed with autism also meant an increase in the number of relatives with a family member diagnosed with autism.

The 1983 Mental Health Act included a broad definition of 'mental disorder': 'this definition can include a person with mental health problems or someone who is learning disabled. Throughout this report, therefore, wherever the term "mental disorder" is used it must be taken to refer to both groups.' However, the report also stated that the 'needs and rights' of people with a mental health problem or a learning disability 'are often distinctly different from one another'.<sup>22</sup>

The 28 February 1985 Report of the Committee of Social Services on Community Care for Mentally Ill and Mentally Handicapped explored the distinction between the two categories in detail:

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<sup>20</sup> The National Archives, DHSS: Community Care for Mentally Ill and Mentally Handicapped, FD 7/2339, DHSS, The Needs of Autistic People and their Families: A Seminar at the Kings Fund Centre Sponsored by the Department of Health and Social Security. 12 March 1985. Programme and Papers, *Extract from Report of the Social Services Committee* (28 Feb 1985).

<sup>21</sup> Bonnie Evans, 'How Autism became Autism: The Radical Transformation of a Central Concept of Child Development in Britain', *History of the Human Sciences*, 26:3 (2013), pp. 3-31.

<sup>22</sup> MIND and Liberty, *People with Mental Health Problems and Learning Disability* (London, 1993), p. 6.

The distinction between the two categories is generally plain enough. Severe mental illness covers a range of mental disorders usually beginning during adult life, which may fluctuate in severity and lead to chronic disability but which are usually amenable to treatment and often clear up completely. Mental illness affects people of every level of intelligence. Mental handicap, on the other hand, is nearly always present from birth or early childhood. It is irreversible, although the effects can be minimised by training, environmental influences and personal help. There is however a potentially confusing degree of overlap. Some mentally handicapped people also suffer from mental illness. Some mentally ill people are in effect handicapped where their disorders are severe and chronic. Some of their needs – for privacy, protection from others and themselves – are similar. In the recent past, policy consideration was sometimes given to both categories together: for example, the Royal Commission which reported in 1957 and the consequent 1959 Mental Health Act dealt with the law relating to 'Mental Illness and Mental Deficiency'. For most purposes, however, we consider that the two categories are best considered separately, although the conclusions reached are often strikingly similar. Throughout this report we use the phrase 'mentally disabled' or 'mental disability' to cover both mentally handicapped and mentally ill people, in preference to the departmental terminology of 'mental disorder'.<sup>23</sup>

*Caring for People: The Next Decade and Beyond* (1989) considered community care priorities for the mentally handicapped separately from the mentally ill, with mental illness given a chapter in its own right because of concerns

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<sup>23</sup> TNA, FD 7/2339, Copy of the report: House of Commons Social Services Committee. Session 1984-85. CC with special reference to adult mentally ill and mentally handicapped people, vol. 1, p. xi.



over a lack of service provision.<sup>24</sup> The white paper did, however, state the expansive remit of community care as 'providing the services and support which people who are affected by problems of ageing, mental illness, mental handicap or physical or sensory disability need to be able to live as independently as possible in their own homes, or in "homely" settings in the community.'<sup>25</sup> Community care initiatives considered the distinct needs of people with mental illnesses and people with mental handicaps. These two groups, however, remained connected by their inclusion within the 'user' groups of community care services. By the 1990s, people with a mental illness or a learning disability were entitled to a needs-based assessment which considered their needs as an individual, as interested in the severity of their condition, and their ability to be independent, as in their diagnosis or classification.<sup>26</sup>

In the early 1990s researchers and policy makers became concerned with another complexity between mental illness and learning disability: the high prevalence of mental health problems for people with learning disabilities. The Judith Trust was established in 1997 as a charity which aimed 'to improve the quality of life of people with both learning disabilities and mental health needs'. The charity was named after a woman called Judith who had been diagnosed as 'having schizophrenia in a woman of low intelligence.'<sup>27</sup> M. Lindsey stated in 1997 that, 'it has been widely shown that the rate of disturbed behaviour and of handicapping psychiatric disturbances, such as autism, is greater in children with

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<sup>24</sup> Department of Health and Department of Social Security, *Caring for People: Community Care in the Next Decade and Beyond* (London, 1988), Cm. 849, pp. 12-13, pp. 53-8.

<sup>25</sup> *Caring for People*, p. 3.

<sup>26</sup> Disabled Persons (Services, Consultation and Representation) Act (London, 1986).

<sup>27</sup> See, Zarrina Kurtz, *Joined Up Care: Good Practice in Services for People with Learning Disabilities and Mental Health Needs* (London, 1999).

learning disabilities.’<sup>28</sup> The 1993 report *Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs* stated that ‘between 25 and 50% of adults [with a learning disability] have additional mental health needs.’<sup>29</sup>

In summary, between the 1940s and the 1990s both mental illness and mental handicap were included in mental health legislation and community care policies. Despite key distinctions between the two categories, the two classifications shared a similar, if often disjunctive, chronology in terms of responses from interested parties, including policy makers. However, the boundary between the two classifications was often indistinct and open to contestation; far more so than one would expect given the tendency to address them as separate histories. The history of the family carer is an interesting point of continuity and tension for the post-war history of mental illness and learning disability; indeed, the coming to the fore of the problem of care is arguably a key factor in the way these two histories come back together in this period. The history of learning disability tends to be omitted from histories of mental health care. This is beginning to change, but the topics are still considered as largely separate. The history of community care requires that this balance be redressed, not least because both groups were often affected by the same legislation. The history of family carers presents an opportunity to do so. During the post-war years the treatment of both severe mental handicap and severe mental illness increasingly became focused on care rather than cure, and the family carers of both groups came increasingly into

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<sup>28</sup> M. Lindsey, ‘Emotional, Behavioural and Psychiatric Disorders in Children’, in O. Russell (ed.), *College Seminars in Psychiatry: Learning Disability* (London, 1997), pp. 81-104.

<sup>29</sup> J.L. Mansell, *Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs: Report of a Project Group* (London, 1993), p. 4.

view.<sup>30</sup> This history of family care thus exemplifies the post-war history of mental illness and mental handicap in separation.

### **A New Perspective on the History of the Family Carer**

During the post-war years family carers for mental illness and mental handicap became more visible and some of these care-givers became collectivised through parent and carer organisations. Despite this parallel, the chronology differed with changes in provision for people with mentally handicaps tending to precede similar developments for people with mental illnesses. As discussed above, Welshman has argued that this disconnect was a product of the risks associated with the mentally ill and the greater degree of sympathy afforded to the mentally handicapped.<sup>31</sup> Using the case studies of Mencap and the NSF (which were discussed in detail in Chapters Four and Five of this thesis, respectively), I argue that a joint examination of family carers for mentally ill and mental handicap in post-war England and Wales can afford historians new insights.<sup>32</sup> In the context of community care, mental illness and mental handicap came to be seen as distinct specialisms.<sup>33</sup> At the same time, however, the mentally ill and mentally handicapped, along with the elderly and those with physical handicaps, were all beginning to be conceptualised collectively as users of community care provision. In a similar respect, whilst family care-givers for the mentally ill and mentally handicapped often had different

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<sup>30</sup> Thomson, *Mental Deficiency*, p. 2.

<sup>31</sup> Welshman, 'Rhetoric', pp. 206-07.

<sup>32</sup> For detailed histories of Mencap and the NSF see Chapters Four and Five of this thesis.

<sup>33</sup> Anne Rogers and David Pilgrim, *Mental Health Policy in Britain* (Basingstoke, 2001), p. 29.

experiences, both became incorporated under the umbrella term 'carer' in the 1980s.

In the immediate post-war years family care-giving for mental handicapped children was considerably more visible than care-giving by families of the mentally ill. A main reason for this was that community care for mental deficiency predated community care for mental illness.<sup>34</sup> During and after the Second World War theories about the significance of bonding between parents, in particular mothers, and their young children were prevalent.<sup>35</sup> In addition, experiments in the community care of mental defectives, a lack of places in mental deficiency hospitals, and the 'ineducability' of subnormal children under the 1944 Education Act meant that more children with mental handicaps were being cared for at home, and that those who were already in the home became more visible.<sup>36</sup> During the 1940s, 1950s, and 1960s parents of handicapped children were increasingly given guidance on how to look after and train these children in the home, a phenomenon which was encouraged by parent organisations including the National Association for the Parents of Backwards Children (NAPBC) and the Spastics Society. The family home and the love and bond of parents with their children within this setting came to be conceptualised as a therapeutic environment promoting the development of mentally handicapped children. In turn, this environment began to be replicated in institutional settings with the model of hostels or homes. Indeed, in the 1970s

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<sup>34</sup> Thomson, *Mental Deficiency*, pp. 194-95; Thomson, 'Sterilization', p. 490; Walmsley, Atkinson, and Rolph, 'Community Care', pp. 181-203.

<sup>35</sup> Angela Davis, *Modern Motherhood: Women and Family in England, c. 1945-2000* (Manchester, 2012), pp. 112-36; Harry Hendrick, *Child Welfare: England 1872-198* (London and New York: Taylor and Francis, 1994), p. 15; Mathew Thomson, *Lost Freedom: The Landscape of the Child and the British Post-War Settlement* (Oxford, 2013), pp. 79-105.

<sup>36</sup> For a more detailed examination of the decline of institutional care for mentally handicapped children, see Chapter Four of this thesis.

Maureen Oswin, a teacher in a cerebral palsy unit, wrote about the negative impact of long-stay institutions. As opposed to a family, or family-like, environment, afforded by family homes and hostels, respectively, mentally handicapped children in large institutions lacked nurture and mothering from a young age, which hampered their development.<sup>37</sup>

During the 1940s and 1950s the care of the mentally ill within the family was a largely hidden phenomenon.<sup>38</sup> With moves towards the closure of long-stay mental hospitals, spurred on by the 1959 Mental Health Act, the 1961 Water Tower speech, and psychotropic drugs, the role of these families began to come into view. By the 1970s these families, in a similar pattern to those that joined the NAPBC, began to collectivise in parent organisations, such as the National Schizophrenia Fellowship (NSF). The NSF, as opposed to the NAPBC, was incepted because of notions that the pathological family was often the cause of mental illness.

The NAPBC and the NSF were incepted in response to moves towards community care which was perceived by many as a move towards care *by* the family. The NAPBC parents were more willing than those who joined the NSF to accept this caring role. The NAPBC's parent-members considered themselves to be parents first and foremost, who had a responsibility and duty to care for their children. Even once the term 'carer' had emerged, Mencap tended to refer to the core of its membership as parents. Parents who cared for their children at home often felt a responsibility for their condition because of guilt associated with hereditary understandings of mental handicaps. These parents were given strong

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<sup>37</sup> Deborah Cohen, *Family Secrets: Shame and Privacy in Modern Britain* (Oxford, 2013), pp. 118-19; Maureen Oswin, *The Empty Hours: A Study of the Week-end Life of Handicapped Children in Institutions* (London, 1971).

<sup>38</sup> Enid Mills, *Living with Mental Illness: A Study in East London* (London, 1962), p. 90.

messages by charities and some medical professionals and social workers that they could effectively nurture and train their children. In addition, these parents often became spokespeople for their children, supporting their education, and having influential interactions with medical professionals.

Similarly to the NAPBC families, the NSF parents tended to become a part of their child's treatment. They engaged in family therapy. They were also keen to demand better services and treatment for their children. They were, however, much more likely to view caring for their child as a burden. The NSF parents reacted against the sentiment, associated with the anti-psychiatry movement, that schizophrenia resulted from repressive families and over-protective, or schizophrenogenic, parents. The on-set of schizophrenia does not tend to occur until adolescence, or later, by which time contemporary opinion dictated that it was healthy for children to become independent from their families. Although schizophrenia can be a severe, chronic, and debilitating illness, hopes for psychotropic drugs to control, or even cure, the condition meant that the degree of care people with schizophrenia needed was often underestimated during the 1970s.

The readiness of the NAPBC parents to actively seek to care for their mentally handicapped children, as opposed to the NSF parents' desire to reject the burden of care for their mentally ill children is likely attributable to the age of onset. Mental handicaps tended to be congenital and perceived as life long, whereas mental illnesses presented themselves later in life and were thought to be curable. The therapeutic role of the parents of mentally handicapped children was supported by medical professionals more so than in the case of mental illnesses.

Class is another key factor here, with the NAPBC membership comprising mainly of working-class families and the NSF of middle-class families. Working-class families were more likely to uncritically accept the caring role without perceiving it as a burden.<sup>39</sup>

The care-giving role of families with a mentally handicapped or mentally ill relative became more visible in the post-war years, in part because of moves towards community care, but also because families were increasingly thought to hold the potential of therapy, training, and support for those with mental handicaps and mental illnesses. For community care to work successfully, rehabilitation and normalisation were key. The Medical Research Council's Social Psychiatry Unit (SPU), were keen supporters of the therapeutic potential of the family.<sup>40</sup> The broad remit of the SPU, and its positioning between sociology, psychology, and psychiatry, enabled their researchers to investigate both mental illness and mental handicap, with John Wing researching schizophrenia, Lorna Wing interested in autism, and Jack Tizard focusing on sub-normality. As stated by the SPU's Aubrey Lewis, 'boundaries between branches of knowledge are vicious if they hinder true research.'<sup>41</sup>

Not everyone, however, supported the continued relationship between research and social policy related to mental illness and mental handicap. The lack of funding for community care initiatives and services resulted in some interested parties campaigning for the needs of the mentally handicapped to be considered

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<sup>39</sup> Steve Humphries and Pamela Gordon, *Out of Sight: the Experience of Disability, 1900-1950* (Plymouth, 1992), pp. 15-16; Mills, *Mental Illness*, p. 148.

<sup>40</sup> For a more detailed examination of the Medical Research Council's Social Psychiatry Unit see Chapter Two of this thesis.

<sup>41</sup> Aubrey Lewis, 'Social Aspects of Psychiatry', *Edinburgh Medical Journal*, 58 (1951), pp. 214-47.

distinctly from the mentally ill. The council of management of the National Society for Mentally Handicapped Children (NSMHC, previously NAPBC) replied to a critical letter from the head of the Bedford local branch, Mr Nickson, in 1975:

the NAMH . . . is a federation of largely professional bodies dealing with mainly the mentally ill, though they do still claim to cater for the mentally handicapped as well; the confusion in the public mind is kept up by the stubbornness of the NAMH in refusing to allow us to entirely take over all activities on behalf of the mentally handicapped, and by their (advertent or inadvertent) dishonesty in using statistics which include mentally subnormal to illustrate problems and solutions confined to the mentally ill!<sup>42</sup>

The NSMHC appear critical of the continued conflation of the needs of the mentally handicapped, with the needs of the mentally ill by the NAMH. From the mid-1970s onwards, however, the growing emergence of the category of the family carer was, in some respects, serving to further destabilise the distinction between the two. The 1976 Social Security Act, which introduced the Invalid Carers Allowance, defined entitled claimants as needing to be, 'regularly and substantially engaged in caring for a severely disabled person'.<sup>43</sup> The key factors were whether the condition of the person they were caring for was considered a disability and the level of severity of this condition, rather than the classification or diagnosis of the condition in and of itself. This legislation was an important milestone in the

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<sup>42</sup> Bedford and Luton Archive and Record Service, Records of Bedford Mencap, X682/4/1, Correspondence concerning the general direction in which the National Society of Mencap is heading, May 1974-Mar 1975, *Correspondence* (February 1975), p. 2.

<sup>43</sup> Department of Health and Social Security, *Social Security Act*, (London, 1975), Chapter 14, p. 1089. For a more detailed examination of the Invalid Care Allowance, see Chapter One of this thesis.



acknowledgement that carers were often unable to sustain paid employment and contribute fully to the labour market.<sup>44</sup>

As argued throughout this thesis, as the category of the family carer emerged, the influence of parents' organisations, social policy makers and social researchers focused attention on the well-being of carers. As more research and discussion focused on the needs of community care service-users, consideration of the needs of carers increased. If family carers were to provide effective care and support, their needs needed to be supported. The research of the SPU into Expressed Emotion argued that carers could become susceptible to mental illness themselves, and exacerbate the symptoms of schizophrenia in their relative, if they did not have adequate breaks and support.<sup>45</sup>

Research into informal carers, along with social security payments for carers, disaggregated the care given to people with disabilities from the care-giving that occurred in a 'normal' family.<sup>46</sup> By this stage, however, a national picture of the number, and types, of carers had not emerged. Concerns over an ageing population led to the first General Household Survey (GHS) study of Informal Carers in 1985.<sup>47</sup> That the GHS was concerned with old age suggests that whilst carers of the mentally ill and mentally handicapped were included in the survey remit, the main drive behind the research was demographic change. The GHS defined informal carers as 'people who are looking after, or providing some regular service for, a sick,

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<sup>44</sup> In Chapter One of this thesis I develop this idea in relation to the entry of women into the labour market and the dismantling of the male bread-winner model.

<sup>45</sup> For more on expressed emotion see Chapter Two of this thesis.

<sup>46</sup> Peter Willmott, *Social Networks Informal Care and Public Policy* (London: Policy Studies Institute, 1986), p. 6.

<sup>47</sup> For a more detailed analysis of the General Household Survey's research into informal care see Chapter Two of this thesis.

handicapped or elderly person living in their own or in another household.<sup>48</sup> The reports that followed the 1985 and 1995 surveys stated that there were 6 million, and 5.7 million carers in Britain, respectively.<sup>49</sup>

As argued in Chapter Two, the 1990 GHS identified a 'spike' in the number of carers, an abnormality which was attributed to more people, especially people providing relatively little amounts of care, self-identifying as carers.<sup>50</sup> As a consequence, the 1995 survey design distinguished informal helpers from informal carers and for the first time asked respondents to specify the amount of hours they spent caring. From this point onwards the hours spent caring and the nature of the help provided, rather than the condition of the person being cared for, became key definers when identifying people under the umbrella term of carer. The state was concerned about categorising people as needing social security payments and instead wanted to encourage more people to enter the labour market. The state wanted to encourage relatives to become carers but was also wary to limit carer numbers; hours spent providing care was a helpful indicator for these purposes. At the same time, medical and educational classifications of mental illness and learning disability were in flux, as evidenced by updates to the Diagnostic and Statistical Manual.<sup>51</sup> Further, as severe mental illness and learning difficulties became classified as disabilities, the severity and chronicity of the disability became increasingly significant, particularly in terms of benefits.

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<sup>48</sup> Hazel Green, *Informal Carers: A Study carried out on behalf of the Department of Health and Social Security as part of the 1985 General Household Survey* (London, 1988), p. 1.

<sup>49</sup> *Informal Carers* (1988), p. 1; Olwen Rowlands, *Informal Carers: An Independent Study Carried out by the Office for National Statistics as part of the 1995 General Household Survey* (London, 1998), p. vi.

<sup>50</sup> Rowlands, *Informal Carers*, p. vii, p. 40.

<sup>51</sup> See, Ian Hacking, 'Lost in the Forest: Review of DSM-5: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, by the American Psychiatric Association', *London Review of Books*, 35:15 (2013), pp. 7-8.

In part a result of the acknowledgement of the differing needs of dependents and their carers, but also due to the fact that the needs of those identified as family carers themselves varied, individual assessments were increasingly called for. As education, health, and social security professionals and governmental departments strove towards joined-up working to improve the quality and efficacy of community care, the opportunity emerged for carers and dependents to receive assessments of their needs from a range of service providers. These services also became joined-up because of overlaps in the needs of individual users, as in the case of people with learning disabilities who were also diagnosed with a mental illness. The 1995 Carers (Recognition of Services) Act, which did not refer directly to carers of mental illness or learning disability but included these carers within its remit, entitled carers to a needs-based assessment from their local authority.<sup>52</sup> The foreword to the 1999 National Strategy for Carers, *Caring about Carers*, written by Prime Minister Tony Blair, stated that '*We all may need care, or to provide care*', but that '*Caring is personal. It is individual.*' Alongside calls to provide more information, support, and care for this broad group of people providing a vital role as carers, the strategy also began to consider the needs of minority carers and acknowledged that 'carers are a diverse group of individuals.'<sup>53</sup>

By the close of the twentieth century, then, the families of service-users engaged in care-giving activities had been subsumed by the broad category of the carer. Those categorised as informal carers tended to be defined more by the hours they spent caring, the severity of their dependents' condition, and their needs as an

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<sup>52</sup> *Carers (Recognition and Services) Act* (London, 1995).

<sup>53</sup> Department of Health, *Caring about Carers: A National Strategy for Carers* (London, 1999), pp. 3-7, p. 37, p. 42.

individual rather than the diagnosis or classification of the person they cared for.

The 2001 Census of the England and Wales included a question on carers for the first time. The question was worded as:

Do you look after, or give help or support to family members, friends, neighbours or others because of:

- long term physical or mental ill-health or disability, or
- problems related to old age?<sup>54</sup>

Respondents were only required to specify the amount of time they spent caring every week rather than the type of disability of the person they cared for.

Special interest carer organisations, including Mencap and the NSF, continued to operate, however. Despite the permeable boundaries between mental illness and learning disability, the two groups continued to be distinct in many respects. Family carers who joined a carer organisation specifically for mental illness or learning disability were able to find out more specialised and specific information in terms of available services, academic research findings, and to meet with others who shared similar experiences to themselves. Whilst the state increasingly conceptualised the carer on an individual or broad collective level, it is likely that family carers identified themselves in terms of their relatives' disability and were directed to more specialised organisations by the medical or educational professionals that had diagnosed, classified, or stated, their relative. On an

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<sup>54</sup> Census 2001 Questionnaires, 'England Household Form H1', 2001.  
<<http://www.ons.gov.uk/ons/guide-method/census/census-2001/about-census-2001/census-2001-forms/index.html>> (20 May 2014), p. 6.

emotional level, many parents joined carer organisations, like the NSF and Mencap to derive mutual support and to engage in shared experiences. Parents identified themselves in relation to their relatives' needs, rather than as carers more broadly defined. In addition parents continued to want to speak on behalf of their children in medical encounters and they were able to do so with the support of a concentrated lobby and support organisation.

## **Conclusions**

In conclusion, examining the history of mental health care and community care in relation to both mental illness and mental handicap enables us to ask new questions and gain new insights. An examination of the emergence of the family carer for mental illness alongside an examination of the emergence of the family carer for learning disability offers a new dimension not only to the history of care-giving and community care, but also post-war history more broadly, particularly the history of the family and social welfare. Despite a disjuncture in terms of chronology, moves towards community care and new therapeutic approaches to learning disability and mental illness made the parents of mentally handicapped and mentally ill children more visible. Care *by* the community and concerns of social policy decisions and professional viewpoints encouraged some of these to collectivise in parent and carer organisations. Whether parents had a positive or negative attitude to their role, assumed or prescribed, as care-givers was largely down to age of onset of the disability and the social class of the family, rather than

simply the severity of the condition. Professional understandings, definitions, and classifications of mental illnesses and learning disabilities remained in flux throughout the post-war years. This lack of clear definitions and distinctions, along with the state's recognition of the vital role played by family carers, meant that the carer role became increasingly defined by the hours spent care-giving and the caring tasks performed. Hours of care was more straightforward to measure and compare than other definers of the carer. Although the boundary between the two was ambiguous, there nevertheless remained clear, persistent and even extended, distinctions between the broad categories of mental illness and learning disability. In some respects, carer organisations ironically played a key role in this. These specialist carer organisations continued to offer family carers mutual support and advice, helping to create a social identity and emotional community, even once the role of the carer became increasingly viewed as a highly personal experience with individual needs-assessments being provided for both carers and their dependents being introduced by the close of the twentieth century.

# Conclusion

## Thesis Summary and Discussion

The central argument of this thesis has been that whilst familial care-giving for people with mental illnesses and learning disabilities can be traced back to the nineteenth century and beyond, a new category emerged out of the post-war English and Welsh context, that of the 'carer'. In some respects, the notion of the carer, which was to enter widespread usage in the 1980s, differed from previous understandings of family care-giving, but there were also continuities. During the post-war years, I argue, it was not only understandings of familial care-giving that were in flux, but also the day-to-day experiences of those relatives providing this care. The place of the family in mental health care was changing too.

The key question addressed throughout this thesis has been the ways, and the extent to which, the family carer emerged in the field of mental health care in post-war England and Wales? Ian Hacking's theories of 'dynamic nominalism', 'moving targets', and 'looping effect', related to his 'Making Up People' project, were used as the starting point for answering this question. As explained in the introduction to this thesis, with dynamic nominalism the classification emerges at the same time as the kind of person or class. As 'moving targets', these new

categories of people continue to be changed, and this, in turn, can trigger a 'looping effect' as 'names interact with the named'.<sup>1</sup>

### **i. Making Up the Carer?**

I will now address the question of whether Hacking's theories do indeed provide a helpful framework to better understand the place, and emergence, of the family carer in English and Welsh mental health care in the post-war period. What is clear is that what we might call a strong social constructionist approach has some serious limitations. For example, if the thesis had followed the approach adopted by Bill Bytheway and Julia Johnson, who have written on 'the social construction of the carer', it would have risked overlooking or downplaying the significance of the day-to-day experiences of familial care-givers and the long history of family care-giving to be examined. However, Hacking offers a more nuanced approach, and this has indeed proved more helpful.

According to Hacking, it is not just the category (in this case 'carer') which is important, but also the categorisation. In this respect the classification, the classifiers, and the people classified are all worthy of study. As sociologist Richard Jenkins has suggested, 'the name can stay the same - "X" - while what it means in everyday life to be an "X" can change dramatically. Similarly, the experience may stay relatively stable while the name changes. Both can change.' Indeed, for this reason, 'family care-giver' is not wholly distinct from 'family carer', in terms of definition or lived experience. By drawing upon Hacking's theories, however, I have

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<sup>1</sup> Ian Hacking, 'Making Up People', *London Review of Books*, 28:16 (2006), pp. 23-26.



been able to examine the, at times, subtle distinction between familial care-giving, which has a long history, and 'family carer', a more recent phenomenon, in a meaningful way. As Hacking stated in relation to his work on child abuse: 'there were plenty of child abusers about in 1900. But that classification, *our* classification, was not yet in place.'<sup>2</sup> Dynamic nominalism comes into play here as the process of classification itself has an impact: 'labelling does not occur in a vacuum' and can offer 'new ways for people to be.'<sup>3</sup> In the case of the family carer, the inception of parent and carer groups, social scientific research, and moves towards community care, meant that understandings of, and the reality for, family care-givers was in flux before the term 'carer' entered widespread usage. Indeed, the 1976 Invalid Care Allowance provided an approximation of the definition of informal carer which would emerge by the 1985 General Household Survey, without actually using the word 'carer'. What these two documents had in common, however, was that they defined care-givers as spending thirty-five hours a week caring, suggesting that this was above and beyond normal familial care. Whilst families have provided care for the mentally ill and mentally handicapped for centuries, this group were newly 'seen' in the post-war years. As such the history of the term, role, and identifier of 'carer' should be seen as one of emergence.

As I have explained above, family care-givers, and those interested in this group of individuals, negotiated, and in some cases rejected, the category of the 'carer'. Campaigns for married women to receive Invalid Care Allowance payments, the National Schizophrenia Fellowship's campaign to extend the rights of the

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<sup>2</sup> Ian Hacking, *The Social Construction of What?* (Cambridge, 1999), p. 160.

<sup>3</sup> Ian Hacking, 'Making Up People' in Mario Biagioli (ed.), *The Science Studies Reader* (London and New York, 1999), p. 161, p. 168.

Nearest Relative, the findings of the General Household Survey, and Mencap's persistent use of the word 'parent' to refer to its members, all served to ensure that the family carer was a moving target. There was, and continues to be, a subsequent looping effect with, for instance, growing recognition of male carers and carers from ethnic groups, extended rights for carers, and a recognition that family members do not have to provide thirty-five hours of care for their relative with a mental illness of learning disability for their lives to be adversely affected. By the close of the twentieth century, the 'vital role' of informal carers had been acknowledged, but the definition and role of the family carer in mental health care continued to be adapted and refined.

Hacking has himself stated that no two instances of making up people are the same.<sup>4</sup> As such, by taking his theories as a loose framework for the analysis of this thesis, I have accounted for the idiosyncrasies of the case study of the emergence of the family carer in the context of mental health care and ensured that Hacking's theories have been useful rather than restrictive as they may likely have been had they been treated as a rigid framework. Some have suggested that Hacking's making up people project is no longer relevant, especially as the neurosciences become a more popular approach to understand what it is to be human. However, Hacking either focused on historical examples or instances that were unfolding 'before his eyes'. It is unlikely to be a coincidence, therefore, that Hacking's approaches are helpful for the case study of the 'family carer', a classification which was emerging when Hacking's making up people project was in full swing.

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<sup>4</sup> O. Madsen, J. Servan and S. A. Øyen, "'I am a philosopher of the particular case': An interview with the 2009 Holberg prizewinner Ian Hacking", *History of the Human Sciences*, 26:3 (2013), p. 37.

## ii. Key Themes

The story of the emergence of the family carer is not one of straightforward change, not least because even once the term 'carer' entered widespread usage by the 1980s, the day-to-day experiences of these so-called carers, or care-givers continued to change. The Oxford English Dictionary defines 'emergence' as 'the process of coming forth, issuing from concealment, obscurity, or confinement . . . the result of the evolutionary process'.<sup>5</sup> To speak of the emergence of the family carer is to refer to a continuing process with a long history. As discussed in the thesis introduction, family care-giving, including in the mental health context, has a long history stretching back many centuries, but it was not until the post-war years that the term 'carer' came into widespread use.

This is a story of change over time. Whilst the story of the emergence of the family carer precedes 1946 and continues today, the start and end date of 1946 and 1999, respectively, were chosen for this thesis because the second-half of the twentieth century was a particularly dynamic period for understandings and experiences of family care-givers. In light of the vast literature on the relationship between the family and mental illness in the nineteenth century, I do not suggest the role of the family in mental health care began in 1946. Rather, I suggest that the period from 1946 to 1999 was characterised by unprecedented debate, research, education, politicisation, and mobilisation around the issue of family care-givers.

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<sup>5</sup> OED Online, 'Emergence', September 2014. Oxford University Press, September 2014. <<http://www.oed.com.pugwash.lib.warwick.ac.uk/view/Entry/61129?redirectedFrom=emergence>> (6 November 2014).

This triggered, and was facilitated by, a new language of care, not least the emergence, by the early 1980s, of the term 'carer'.

I will now summarise the four main arguments of this thesis. Firstly, I have demonstrated that from the work of the Institute of Community Studies onwards, social scientific researchers, using new tools and methodologies developed during the Second World War, began to enter the family home and uncover the previously hidden world of mental illness and learning disability within the family. Although often not directly interested in familial care-givers from the outset, these researchers became interested in family dynamics and the well-being of care-givers. By the time of the General Household Surveys of 1985, 1990, and 1995, it emerged that there were around six million such carers. Sometimes, influenced by this social research, the media also began to enter the family home with the experiences of family care-givers being represented to the public via documentaries and documentary-dramas, often in conjunction with parent and carer groups. This was important in bringing the idea of the family carer, and of the importance of family care in relation to mental health, to a new state of public attention.

Secondly, I have attempted to cast light on changing understandings of this social character of the carer. I have argued that in the immediate post-war years family care-givers were defined in large part by their dependent. Initially, for instance, the severity of the relative's condition was used as an indicator for the extent of care the relative would need to provide. However, in line with the breadwinner model of the welfare state, family care-givers were also assumed to nearly always be women. This notion was later called into question, but was not wholly dispelled, by second-wave feminists and sociologists reviewing the findings

of the General Household Survey's reports on Informal Carers. Social research turned attention to carers in their own right. It often found that families from working-class backgrounds were less likely to seek professional help than middle-class families, who were more likely to reject the burden of care and seek outside assistance. The fact that the membership of the National Schizophrenia Fellowship was mainly drawn from middle-class families would seem to support such claims. However, it seems that Mencap initially had a membership of predominantly working-class families. This indicates that more work is needed to establish the veracity of contemporary assumptions about class profile of the carer, and that there will be a challenge in attending to the complexity of relations between class and care in an era of shifting class identities and changing popular attitudes to state and voluntary intervention.

By the mid-1970s the hours a week spent caring were key to defining an individual as a family care-giver and only those caring for thirty-five hours a week could claim state benefits. However, by the late-1990s family carers for mental illness and learning disability had been largely subsumed within the broader category of the carer and carers were now defined by their individual needs and circumstances, rather than the severity of the condition of their relative. The needs and well-being of carers was assessed in terms of their gender, class, race, age, and whether or not they were in employment. At the same time, carers were given rights to access benefits separately from the person they were caring for. In summary, the period had seen a fundamental transformation from carers being viewed primarily in terms of who they were caring for, to carers being addressed in terms of their own needs.

Thirdly, I have argued that studying the histories of mental illness and learning disability together can afford historians new insights into the post-war period. Although learning disability is often excluded from histories which examine post-war mental health care, learning disability actually had a close, yet complex, relationship to mental health care. The case study of the family carer has demonstrated how studying mental illness and learning disability alongside one another, particularly in terms of the indistinct boundaries between the two categories, can open up new areas of historical study and provide new insights. For instance, this thesis has demonstrated a significant chronological gap between the emergence of the family carer for mental handicap and the emergence of the family carer for mental illness. Indeed, Mencap was set up twenty years before the National Schizophrenia Fellowship, and the *Better Services* white paper for mental handicap was published four years before the one for mental illness. However, by the close of the twentieth century the chronology for family carers for people with mental illnesses and for people with learning disabilities was broadly the same. In short, because of the shift of attention to the issue of care (and perhaps also, relatedly, because of the move to think about the mentally ill as disabled), the post-war period has seen a significant closing of the gap between handling of mental illness and learning disability. This is an issue that has perhaps not deserved the attention that it merits. It is one which perhaps only comes to light so strongly when we turn our attention to the history of care rather than approaching these questions through the medical perspective of the history of psychiatry.

Fourthly, I have demonstrated that over the course of the post-war years the issue of family care-giving became increasingly politicised. The introduction of a

state policy of community care in the early 1960s led to widespread concern that care *in* the community would in reality mean care *by* the community, or more specifically, care *by* the family. As the post-war years progressed, carers in England and Wales came to be officially recognised by the state, with for example the introduction of social security benefits, the Carers (Recognition and Services) Act (1995), and the National Strategy for Carers (1999). However, this official recognition was largely a result of concerns about the ageing population, with much of this social policy being created with the specific aim of helping family carers for relatives in old age. There is scope for this broader history of the carer, including old age and physical disability, to be pursued in more detail, not only for the post-war English and Welsh context, but for post-war Britain. Demographic change and concerns over an ageing population were of keen importance to actors in post-war Britain who were concerned about its impact, especially in the context of the rediscovery of poverty, increased levels of women's employment, and growing economic pressure on the welfare state.

In the era of community care, the state became increasingly aware of the important role families played and in this respect the histories of community care and family care are closely linked to one another. Although an expectation that family members should care for their ill, sick, elderly, or disabled relatives was not novel to the period after the Second World War, these expectations were more clearly articulated to parents and families in post-war England and Wales. However, largely due to a sense of welfare entitlement, carers and carer organisations now began to lobby and campaign for rights for carers, including the right to refuse to provide care. By the 1990s, the rights of carers were beginning to be recognised by

the state. At the same time, along with service-users and people with learning disabilities, carers were increasingly recognised as key partners in ongoing development of mental health care. Campaigning efforts to maintain and extend the rights and well-being of carers continues today.

This thesis has focused on the key events, episodes, and issues which brought about the emergence of the family carer. It has been shown that this process took place in the following contexts: social policy, social research, the media, parent and carer groups, and mental health care. These different contexts have constituted the various chapters of this thesis, with each one exploring some of the factors which led to the emergence of the carer. This section of the conclusion has drawn together these factors to assess which of the contexts examined was the most important to the emergence of the family carer in post-war England and Wales.

A state policy of deinstitutionalisation and community care was ultimately crucial in providing the context for family care-givers coming to be defined as 'carers' and coming to be an object of further policy decisions and new legislation. As a result, whether or not care *in* the community was always intended to mean care *by* the family, by the end of the twentieth century family carers were recognised as playing 'a vital role' in community care. This was an important change in the history of British mental health care. However, these social policy developments did not occur within a vacuum. Firstly, owing to the nature of democracy and citizenship in post-war England and Wales, carer organisations were able to lobby Parliament and influence policy decisions. They were active rather than passive in this history of emergence. Secondly, social research shaped new



phenomena such as the carer, informing not just policy but also through routes such as the media and pressure groups reaching out to the public and the world of the carer itself. The emergence of the category of the carer was therefore shaped, and indeed re-shaped, by a variety of factors in the post-war period. Understanding this process provides us with an important and hitherto largely hidden dimension to the story of the emergence of community care in the post-war period.

### **Epilogue: Unpaid Carers, c. 2000-2011**

The issues surrounding family carers, now often referred to as unpaid carers, continued to be key sites of concern for interested parties, including policy makers, social researchers, and carer organisations in the first decade of the twenty-first century. At the turn of the century, family carers for relatives with mental illnesses and learning disabilities were incorporated within the broad definition of informal or unpaid carers, which encompassed people who cared for the sick, disabled, and elderly. Carer organisations, including Mencap and the National Schizophrenia Fellowship (known as Rethink: Mental Illness from 2004), and televised documentaries continued to highlight the distinct experiences and needs of sub-groups of family carers, such as those caring for individuals with a mental illness or learning disability. Following recognition in a report of the General Household Survey that there were 5.7 million informal carers in 1995, with one in every eight

adults providing informal care, the 1999 National Strategy for carers, *Caring about Carers*, proposed that carers be given more information, support, and care.<sup>6</sup>

Many of the developments in terms of the place of the family carer in mental health care between 2000 and 2011 continued in the vein of the 1999 National Strategy, which reflected many of the hopes and objectives of carer organisations and social scientific researchers during the post-war years. For example, family carers were broadly defined and no longer assumed to be women, carers were recognised as having their own needs as individuals, and carers' well-being was a primary concern, regardless of whether they were caring for thirty-five hours a week or not. Further, many of the themes that were central to the history of the family carer between 1946 and 1999 continued to be relevant. For example, further social surveys had been conducted to examine the characteristics of family carers. And campaigns persisted to provide more support and obtain greater rights and choice for carers. This continued recognition of the need to acknowledge and support carers led to the Carers Acts of 2000 and 2004, although, interestingly, these Acts were both borne out of private member's bills.

The Carers and Disabled Children Act of 2000 was the result of a private member's bill sponsored by Labour MP Tom Pendry. During the order for the second reading of the Bill, Pendry explained how his constituents influenced his decision to campaign on behalf of carers:

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<sup>6</sup> Olwen Rowlands, *Informal Carers: An Independent Study Carried out by the Office for National Statistics as part of the 1995 General Household Survey* (London, 1998), p. vi; Department of Health, *Caring about Carers: A National Strategy for Carers* (London, 1999), pp. 5-6. For a more detailed examination of the General Household Survey's reports on Informal Care see Chapter Two of this thesis. The 1999 Carers Strategy is examined in detail in Chapter One of this thesis.

In Stalybridge and Hyde alone, there are perhaps just under 9,000 carers—roughly one in eight of my constituents. I have been amazed by the amount of support that they have given to elderly, sick or disabled relatives. I have been struck by the fact that, even though they are providing substantial amounts of care, relatively small changes can improve the quality of their lives.<sup>7</sup>

The 2000 Carers Act strengthened the rights of carers over the age of sixteen. It introduced the right for carers to have a local authority assessment regardless of whether the person they were caring for had been assessed. It also empowered local authorities to provide direct payments to carers so that they could choose how to spend their benefits. The Carers and Disabled Children Act was widely criticised for not making enough of an improvement to the lives of carers and, in part, because few carers were in receipt of direct payments.<sup>8</sup> However, the Act did begin to consider the relationship between the carer and the person they were caring for, and specifically focused on the care of disabled children as opposed to the care of adults.

Four years later, the Carers (Equal Opportunities) Act of 2004 responded more explicitly to the rights agenda. The 2004 Act aimed to reduce the disadvantages faced by carers as opposed to non-carers. For the first time, assessments considered carers' ambitions in relation to work, study, training, and leisure. Carers were given the right to information, support, and advice by local authorities, a provision long-campaigned for by carer groups and a specific objective of the 1999 National Strategy for Carers. Furthermore, service providers

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<sup>7</sup> *Hansard's Parliamentary Debates*, 4 February 2000, vol. 343, cols 1335-98.

<sup>8</sup> Lisa Buckner and Sue Yeandle, *Valuing Carers 2011: Calculating the Value of Carers' Support* (London, 2011).

and related authorities were encouraged to co-operate with one another, which led to local and regional differences in implementation.<sup>9</sup>

The 2004 Act was also the result of a successful private member's bill, this time sponsored by another Labour MP, Dr Hywel Francis, with the support of disability campaigner, Lord Ashley. Additionally, Francis had gained relevant experience when he was made vice-president of Carers UK in 2004 and when he became the founding chair of the All Party Parliamentary Group on Carers. Lord Ashley was a prominent disability campaigner. In 1972 he had led a debate in the House of Commons on the Thalidomide Children, a debate which focused on the experiences and hardships faced by the relatives of the affected children. In his introductory remarks to the second reading of the 2004 Bill, Francis explained its personal significance:

On 25 June 2001, in giving my maiden speech, I spoke of a journey of hope, from social exclusion to justice, for people with disabilities and their carers. I made a pledge in that speech to work on their behalf. I begin with that personal note because my wife and I were carers for over 16 years of our son, Sam, who had Down's syndrome and who died nearly seven years ago. In common with millions of carers, the experience profoundly changed our lives.<sup>10</sup>

As with many of the other supporters of family care-givers referred to in this thesis, including social psychiatrist John Wing and campaigner Judy Fryd, Francis had

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<sup>9</sup> *Carers (Equal Opportunities) Act* (London, 2004).

<sup>10</sup> *Hansard's Parliamentary Debates*, 6 February 2004, vol. 417, Cols 1015-76.

personal experience of caring for a disabled child.<sup>11</sup> The 2004 Act was designed to give carers greater agency over their own lives and to equip them with the information they required to make informed decisions. This was part of a broader trend at the time of transforming welfare users, in this case family carers, from passive welfare recipients to an empowered group of individuals who should be given a greater degree of agency to make their own choices.<sup>12</sup>

New Labour perceived carers to be individuals with rights, as well as having responsibilities to their families.<sup>13</sup> However, by making information available to carers and granting them a degree of agency over whether they provided care or not, the 2004 Act was also very much in line with the long-standing objectives of carer groups including Mencap and Rethink. The 2000 and 2004 Acts, along with the 1995 Carers (Recognition and Services) Act, were based on proclamations that family carers were the main providers of community care but also marked an acknowledgement that not all relatives were in a position to provide care. The carer role was still being negotiated with some arguing legislation had not done enough, and others asserting that it had gone too far, advancing the wishes of carers at the cost of disability rights. These arguments were not new, however, having been prevalent earlier, especially during the 1990s, when there was widespread

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<sup>11</sup> More information on Judy Fryd's personal experience as a carer for a child with a learning disability can be found in Chapter Four of this thesis. More information on John Wing's personal experiences as a carer can be found in Chapters Two and Five of this thesis.

<sup>12</sup> Julian LeGrand, *Motivation, Agency, and Public Policy: Of Knights & Knaves, Pawns & Queens* (Oxford, 2006), pp. 81-82. For a similar argument about patient-consumers, see: Alex Mold, 'Making the Patient-Consumer in Margaret Thatcher's Britain', *Historical Journal*, 54:2 (June 2011), pp. 509-28; Alex Mold, 'Patients' Rights and the National Health Service in Britain, 1960s-1980s', *American Journal of Public Health*, 102:11 (November 2012), pp. 2030-38.

<sup>13</sup> Marian Barnes, 'Welfare Users and Social Policy', in Pete Alcock, Margaret May and Sharon Wright (eds), *The Students Companion to Social Policy* (4th edn, Chichester), pp. 280-81; Catherine Bochel, 'State Welfare' in Pete Alcock, Margaret May and Sharon Wright (eds), *The Students Companion to Social Policy* (4th edn, Chichester), p. 213.

recognition of the separate needs of family carers, on the one hand, and service-users and people with learning disabilities, on the other.

From 2010, the newly elected Conservative and Liberal Democrat coalition government continued to recognise the importance of family carers to community care provision and the need to support this group to continue to fulfil this role. The Conservative manifesto of 2010 showcased the Party's policy of increased civic participation: 'we need a new approach: social responsibility, not state control; the Big Society, not big government.'<sup>14</sup> The manifesto acknowledged that an important aspect of the Big Society would be the continued role of unpaid carers. Families had fulfilled this role for centuries, although understood via different terminology and not always with explicit recognition or public awareness. The Conservatives set out their intention for the state to support the role of family carers:

The UK's six million carers play an indispensable role in looking after friends or family members who need support. Not only do they provide help to some of the most vulnerable people in society, the unpaid work they do contributes £87 billion worth of value a year – sometimes at the cost of carers' finances and even their health. We will support carers, and those they look after, by providing direct payments to help with care needs and by improving access to respite care.<sup>15</sup>

In 2010 an update of the National Strategy for Carers was published, entitled: *Recognised, Valued, and Supported: Next Steps for the Carers Strategy*,

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<sup>14</sup> Conservative Party, *Invitation to the Join the Government of Britain: The 2010 Conservative Party Manifesto* (London, 2010), p. 35.

<sup>15</sup> Conservative Party, *Invitation*, p. 48. See also, L. Buckner and S. Yeandle, *Valuing Carers: Calculating the Value of Unpaid Care* (London, 2007).

which stated, in line with Coalition government policy, that carers 'embody the spirit of the Big Society.'<sup>16</sup> This rhetoric was, in fact, very similar to Labour's National Strategy of 1999, where carers were described as 'unsung heroes' and 'a vital part of the fabric and character of Britain'.<sup>17</sup> However, as has been demonstrated throughout this thesis, a rhetoric of recognition of and increased value placed on the family carer did not necessarily translate into changes to the everyday experiences of the relatives of those with a mental illness or learning disability.

For the second time, in 2011 the Census of England and Wales sought to map the extent and nature of unpaid carers. The 2011 Census found there were 5.8 million unpaid carers for the sick, disabled, and elderly in England and Wales, which accounted for twelve per cent of the population and an increase of 600,000 informal carers since the first census snapshot had been taken of this group in 2001. The largest growth between the 2001 and 2011 Census was in unpaid carers, who provided fifty or more hours of care per week.<sup>18</sup> However, as the NSF had long sought to point out, hours spent caring was not always the best indicator of the impact of care-giving on families. The negotiation of the category of the carer and the place of the carer in mental health care continues. Indeed, by 2010, little progress had been made to develop and expand the social-policy agenda beyond the ideas that had been outlined in the 1999 National Strategy for Carers. Whilst this lack of progress might suggest that the carer has now emerged, the emergence

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<sup>16</sup> Department of Health, *Recognised, Valued, and Supported: Next Steps for the Carers Strategy* (London, 2010), p. 3.

<sup>17</sup> *Caring about Carers*, pp. 3-5.

<sup>18</sup> Chris White, *2011 Analysis: Unpaid Care in England and Wales: 2011 and Comparison with 2001* (Newport, 15 February 2013).

of the carer continues with social scientific researchers and carer organisations continuing to challenge and negotiate the category of the carer based on the day-to-day experiences of family carers.



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